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The “Hidden” and the “Invisible”: The Lived Experiences of Farming Dyads with Stable Angina Pectoris

A longitudinal, hermeneutic phenomenological study

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The “Hidden” and the “Invisible”: The Lived Experiences of Farming Dyads with Stable Angina Pectoris

A longitudinal, hermeneutic phenomenological
study

Stephen Thomas Heptinstall

A thesis submitted for the degree of Doctor of Philosophy

University of Bath
Department of Psychology

June 2015

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**Abstract: The “Hidden” and the “Invisible”:
The Lived Experiences of Farming Dyads with Stable
Angina Pectoris**

Stable Angina Pectoris (SAP) pain is caused by decreased blood flow to the heart muscle. It is exacerbated by exertion and eased with rest. Research indicates the need to improve support given to sufferers (NACR, 2008) that considers ethno-cultural factors (King et al., 2006) and close relational influences (Dalteg et al., 2011). However, delivery of appropriate care in isolated rural communities remains challenging. Despite agriculture being recognised as one of the most dangerous occupations, with above average incidence of chronic conditions and mental health issues, the profession remains medically under-served, due to geographic and attitudinal restraints (Anderson et al., 2012). The impact SAP has on male farmers, who rely on a physically active body, and their female partners who sometimes, though not always, work on the farm, is poorly understood. Hence, this study sought to investigate the lived experiences of eight Herefordshire male-female farming couples where the man had SAP, to help inform future care.

Using a longitudinal, hermeneutic phenomenological research design, data were obtained through semi-structured interviews, on three occasions, over twelve months. Lifeworld existential dimensions, corporeality, spatiality, temporality, relationality were used to categorise findings and draw analytic interpretations, alongside the embodied reflections of the researcher.

This study found that couples practised bodily subterfuge, in order to manage vulnerabilities inconsistent with their worldview. The men with SAP attempted to hide body disruption, to maintain their sense of self and social standing. The women became body invisible, to conform to dutiful care-giving, supplement their partner's farm-work, and distance themselves, inter-corporeally. Disharmony between body, self and world, during illness, also eroded the participants' sense of existential trust.

This research demonstrates the importance of acknowledging the existential lifeworld of both the individual farming male with SAP and their female partner. It also offers a threshold whereby more targeted, humanised healthcare may proceed.

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List of Abbreviations

AHA	-	American Heart Association
ACC	-	American College of Cardiology
APA	-	American Psychology Association
BHF	-	British Heart Foundation
CABG	-	Coronary Artery Bypass Graft
CHD	-	Coronary Heart Disease
CNS	-	Clinical Nurse Specialist
CR	-	Cardiac Rehabilitation
CVD	-	Cardiovascular Disease
FMD	-	Foot and Mouth Disease
GP	-	General Practitioner
GTN	-	Glycerol Trinitrate
GVA	-	Gross Value Added
HCH	-	Hereford County Hospital
HPCT	-	Herefordshire Primary Care Trust
HSE	-	Health and Safety Executive
IHD	-	Ischaemic Heart Disease
IPA	-	Interpretative Phenomenological Analysis
IRH	-	Institute of Rural Health
LLC	-	Lifeworld-led Care
NACR	-	National Audit of Cardiac Rehabilitation
NHS	-	National Health Service
NICE	-	National Institute of Clinical Excellence
PCC	-	Patient-centred Care
PCI	-	Percutaneous Intervention (angioplasty)
QEH	-	Queen Elizabeth Hospital
RACPC	-	Rapid Access Chest Pain Clinic
RCT	-	Randomised Controlled Trial
SAP	-	Stable Angina Pectoris
SERT	-	Socio-Emotional Relationship Therapy
SIGN	-	Scottish Intercollegiate Guidelines Network

TB	-	Tuberculosis
UK	-	United Kingdom
UOB	-	University of Bath
WRH	-	Worcester Royal Hospital

Dedicated to Graham, Janine and R.B.

‘She glanced at her husband, a look in which Dorrigio glimpsed a complex mud of intimacies normally invisible to the world – the shared sleep, scents, sounds, the habits endearing and frustrating, the pleasures and sadnesses, small and large – the plain mortar that finally renders two as one.’

Richard Flanagan, *The Narrow Road to the Deep North* (2013, 100)

Chapter One: INTRODUCTION

“plastic chairs placed
where angina likes to bite
hidden round the farm”



“Up around where I regularly go, in the calf shed, er, down by the pony paddocks, tied to a gate post, erm, er, up where the rams are and the dovecote, er I had six, seven, dotted round, if I, if I suddenly felt bad I’d sit down, erm, and then a few minutes later I’d be alright, erm, I don’t know if that’s typical?”

George

1. Chapter One: INTRODUCTION

The intention of the Farm Angina Project is to provide a delicate understanding of the lived experiences of eight Herefordshire farming male-female couples, in which the male has Stable Angina Pectoris (SAP) over one year. This chapter acts as a platform to introduce the various concepts related to this study and guides the reader, in a logical manner, into the thesis. To begin with, I give an overview of why the Farm Angina Project was undertaken, followed by an outline of my research questions and the reasons for undertaking a longitudinal, hermeneutic phenomenological approach. In line with my chosen methodology, I then offer a brief overview of my pre-understandings, before finally giving an overview of subsequent thesis chapters.

1.1 Introduction

Contrary to the widely held belief, farming does not mean freedom. It means planning schedules, watching the clock and calendar, long hours at various times of the year and close money flow management; it is not the escape or rural idyll that many office-based people perceive it to be (windrosefarm.org., 2015). Farming can also be physically gruelling and dangerous. The Health and Safety Executive (HSE, 2013, 6) states that approximately 430,000 people work in agriculture, in the United Kingdom (UK), which equates to *“less than 1.5% of the working population, yet agriculture has one of the highest fatality rates of all industries...responsible for between 15-20% of all deaths in Britain each year”*. These are work-related deaths, most commonly due to accidents involving machinery. The HSE (2013) also highlights that work practices in the industry can lead to an array of non-fatal illnesses and disabilities which can take many years to develop. Working with animals, breathing in dust, excessive temperatures, vibration and noise,

as well as having to work with chemicals are all cited as causes of ill health, in this sector. Furthermore, there is growing acknowledgment of the psychological hazards of farming, including high stress levels, linked to an increased incidence of suicide (Fraser et al., 2005). Working within this environment, with its array of stressful circumstances, raises the following questions: How long would a farmer be able to maintain his work role, if he was unfortunate enough develop an illness such as SAP? Limited by heart disease, how would his spouse experience this suffering? What pressures would it place on them both trying to uphold the profitability of the farm and their social standing within the community? Finally, how can a care service that does not take into consideration the specific needs of farming families (King et al., 2006; Clark et al., 2012) ever hope to truly offer effective support?

The purpose of this study is to understand, in depth, the lived experiences of SAP in eight farming dyads, over a twelve month period. This is significant for three reasons. The first is because little research has been published relating to the illness in this specific group of people. Secondly, there have been few studies which have followed the experiential progress of SAP and how this changes, over time, particularly within couples. Thirdly, Herefordshire Cardiac Rehabilitation wishes to provide a care package which is sensitive to the needs of its farming community. A longitudinal, hermeneutic phenomenological research approach was adopted, as this was considered to be a reliable means of obtaining the data required and undertaking a sensitive “bottom-up” analysis over the period of time in question. More specifically, this research contributes to professional knowledge and practice, by providing a detailed view of the existential experiences of farming dyads with SAP; alongside consideration of how these findings might shape a culturally sensitive SAP management programme, that considers couples’ individual lifeworld dimensions.

1.2 Why this Research was Necessary

My interest in the subject of angina in farming was born out of my work as a Cardiac Rehabilitation Practitioner at Hereford County Hospital (HCH) and my intention of introducing a secondary care service for the county's SAP sufferers. This initiative was in response to a national plea to Cardiac Rehabilitation (CR) services to include people suffering with SAP, as evidence suggests current management is sparse (NACR, 2008). In line with the Rural White Paper (Dept. for the Environment, 2000), Herefordshire CR also wished to "rural proof" its services, recognising that different groups of people in rural settings may have different needs, particularly farmers and farm-workers, compared to those who merely live in the countryside. The need to consider the cultural background of patients from communities one might initially consider to be more closely situated, such as white, English-born rural dwellers, soon became apparent. Vaughn et al. (2009, 72) argue that one should not assume cultural difference, based on a language alone: *"culture encompasses more than nationality, race or ethnicity and is intimately related to beliefs and practices"*. According to Davidson et al. (2010), CR needs to embrace cultural competences which allow it to focus upon the unique needs of culturally diverse populations, if it is to increase participation and effectiveness towards such groups. The authors argue that culture impacts both health and health behaviour and therefore, those practising CR need to be *"attuned to the cultural beliefs of their clients"*, in order to support changes related to heart health (Davidson et al., 2010, 1336).

Based on the department's own data, I recognised that recruitment and retention on our existing programmes from those in the farming community was low. Moreover, discussion with farmers and farm-workers who attended these programmes cited work pressure as the main reason for their colleagues' lack of attendance. Certainly, this concurred with the findings of studies exploring barriers to attendance at rural CR programmes (Tod et al., 2001; King et al., 2006; De Angelis

et al., 2008). Perhaps not so impactful in other parts of the country, this was a major concern for CR in this particular county because:

- more than 54% of the population live in rural areas, compared to 18% for England (HPCT, 2008);
- the county has a gross value added (GVA) by agriculture, forestry and fisheries of 7%, compared to just 1% GVA for England (Herefordshire Council, 2009); and
- 1 in 7 people are in agricultural employment (Herefordshire Council, 2009).

Therefore, the question naturally arose that if the CR team hopes to develop a SAP management programme, how is it going to engage effectively with patients from farming communities and cater for their needs?

1.3 The Aim of the Study and the Research Question

The objective of this study was to understand the lived experiences of both the SAP sufferer and their partner from a farming background, so that care may be more sensitively developed to meet their needs. The intention of any new service was to include partners, as numerous studies have highlighted the impact that couples can have on each other's health and wellbeing (Walker and Luszcz, 2009), particularly in relation to heart disease (Mahrer-Imhof et al., 2007; Wood et al., 2008), as well as the detrimental effect illness in one member of a dyad can have on the other, over time. Examples of the importance of relational support have been demonstrated in a number of cardiac-related research papers, such as coronary heart disease (Lidell, 2002; Karner et al., 2004); heart failure (Agren et al., 2009; Rohrbaugh et al., 2009); myocardial infarction (Bennett and Connell, 1998; Svedlund and Danielson, 2004; Eriksson et al., 2009); cardiac arrest (Bremer et al., 2009); and after coronary artery bypass (Robley et al., 2010; Macleod, 2011; Whitsitt, 2009). However, I was unable to evidence any specific research related to dyadic coping with SAP. I, therefore, posed a

straightforward question, namely: *“How does each partner of a farming dyad experience stable angina pectoris?”*

1.4 Selecting the Methodology

It is argued that hermeneutic phenomenology is a research methodology appropriate for describing human experience in relation to historical, social and political forces that shape the meaning of wellness, illness and personhood (Wojnar and Swanson, 2007). Criticisms levelled at health research, in that it is mechanistic, concerned only in the eradication of disease and symptoms, also made me consider this a viable approach. Indeed, Price and Evans (2009), in their review of the determinants of “farm stresses”, call for health researchers to adopt a more holistic perspective of farming life, when attempting to assess how they approach healthcare. Bullingham (2009) also argues that, by using a phenomenological standpoint, one can break free of traditional, medical models and begin to appreciate that pain is not simply a body phenomenon, but an existential one, altering the very nature of the experience of the world and self. Again, as my focus was SAP, an approach that gave me a “holistic” view of this condition seemed sensible. I also recognised that I wanted to capture the temporal and changing nature of the SAP experiences of participants, hence my decision to undertake a longitudinal study.

In this context, Marsh and Furlong (2002) state that the foundations upon which a researcher works are their ontological and epistemological positions. The authors argue that such positioning is not arbitrary, nor selectable, but rather is more to do with the deeply embedded ideals of the researcher and thus, is a metaphorical “skin” that cannot be changed. Significantly, I certainly did not enter my research with that degree of certainty or belief. In truth, method actually directed methodology, during the initial stages of my study. My original intention was to utilise Interpretative Phenomenological Analysis (IPA) to anchor methodology and method, as set out by Smith et al. (2009).

IPA has become a popular qualitative approach within the UK, over the last ten years, particularly within health psychology (Chamberlain, 2011; Finlay, 2011). This is due, in part, to the growing amount of support and training that has been given to emerging researchers “looking for direction” (Chamberlain, 2011, 48). According to Chamberlain (2011), IPA’s appeal is that it offers an accessible method and coding scheme, while at the same time requiring little reflection or acknowledgment of background philosophy. Van Manen (2013) describes such an approach as experiential phenomenology, adopted by professional practitioners “*less interested in the philosophy of phenomenological method than its practice and application*”. However, it is argued that the practice of any form of phenomenology is impossible, without full consideration of its philosophical roots (Giorgi, 2010).

As I grew in my understanding as a researcher, other interpretive approaches influenced my thinking more than IPA and ultimately shaped my methodology and subsequent chosen method, particularly the interpretive work of Van Manen, Karen Dahlberg, with her “lifeworld approach” and Les Todres’s “embodied enquiry”. However, this was a slow and difficult process. My inability to settle upon a method concerned me; I found it difficult to position myself and reconcile that what I had done earlier in my study (i.e. IPA) as now worthwhile. Nevertheless, Saldana (2003, 38) states that a longitudinal researcher’s “*own methodological orientation may change as the longitudinal project progresses through time*”, which might lead some to changes in method midway through a study. He argues that the emergent nature of qualitative research permits this; he also suggests that the researcher’s attunement to their effectiveness or otherwise should be celebrated, not criticised from a misplaced traditionalist viewpoint regarding reliability and validity. Saldana (2003, 43) states “*longitudinal improvements in techniques are admirable researcher tactics*”. Ultimately, I gained confidence from these comments and learned not to be apologetic, but rather to be open and honest about my own research journey.

Similar in some ways to IPA, Van Manen (1990) offers researchers a template for guiding phenomenologists, which I felt myself drawn towards. Applebaum (2010, 48), however, argues that Van Manen's approach to hermeneutic phenomenology is "*beset by multiple internal contradictions, in large part because epistemological clarity, disciplinary and methodological rigor are framed as non-issues*". He highlights Van Manen's (1990, 167) statement that "*there is no research design or blueprint to follow*" and questions why he then offers the reader in the same book a range of data-gathering and analysis procedures. This criticism did not sway me from seeing the worth in Van Manen's approach, as already outlined; however, it did not make it easy for me. In the end, I had to consider my own approach within a value structure, based in hermeneutic phenomenology, taking elements not just from Van Manen, but also noticeably from Dahlberg and Todres. Regardless of criticism from descriptive phenomenologists, such as Giorgi and Applebaum, as to the scientific relevance of such an approach, I could see the worth and power of adopting a hermeneutic phenomenological research approach. The decision to make this a longitudinal study was difficult as there is not much guidance related to undertaking such research from a hermeneutic phenomenological perspective. However, I felt it was important to capture something of the journey participants took with SAP, their evolving experiences over one year, linked not only to illness and healthcare, but also the seasonal demands of a farming way of life.

1.5 Pre-understandings

Hermeneutic phenomenology acknowledges the impartiality of the researcher (Finlay, 2011). It was, therefore, important for me to understand my own positioning, as I entered into the field-work.

I have had an interest in the subject of the body since my late teens. First during my time at Wakefield Technical College, studying fine art and struggle to represent aliveness as well as precise lines during life

drawing. Next as a student of Pinderfields' College of Physiotherapy, where dualism was taught, biology, anatomy and kinesiology my focus. Years later I became a physiotherapist attached to a mental health team in Cardiff, and there I began to consider the impact of psychological aspects on the body. Not only that but the power of others to effect the body through touch. Throughout my career mine has been a journey of layered understanding and discovery. I undertook a MSc. in Pain Management Studies, where the biopsychosocial approach to chronic pain was celebrated. Now as a CR Practitioner I have recognised the need to encompass a new layer of understanding about the body, the phenomenological psychological perspective, the body as subjectively lived, where selfhood and society are interconnected. This has become important because I have struggled to engage with patients from farming backgrounds and understand heart disease from their unique perspective.

I was aware that I began with a number of assumptions related to the treatment of SAP, less so about farming. I recorded initial pre-understandings and fore-projections in my "Reflective Notes" Folder. The first page reads:

"Where do I start? I've been putting this off – uncomfortable with the process - the idea of reflection. Having to stop, reverse, pick over the road already travelled. A challenge? Most certainly".

"I am a physiotherapist with nearly 30yrs of experience – I know about the biopsychosocial aspects of pain. I am a cardiac rehabilitation practitioner – I know about angina, the strangeness of it and its effect upon a person's quality of life. I know people fear it, feel it may lead to a heart attack, and I know this is not necessarily true. I know how it is treated. I do not know anything about farming – I do not know about the lives of couples engaged in this sort of work. I think farming is hard work. I believe it requires dedication, discipline, done as part of a bigger picture; something to do with life, religion, culture. Something I feel uneasy about, and yet view with a certain envy. What does a

strong sense of belonging feel like? I know too that we do not cater for the needs of farmers in cardiac rehab, counting the number of those that fail to attend. We seem irrelevant somehow and that disappoints me. I also know we never see the farmer's wife!" (Researcher reflection, 13/12/10).

I was most concerned that I would not be able to offer anything to this group of people from a rehabilitation perspective, even following my research. This struggle to break free from established practice would be very much part of my own journey.

That said, a certain trepidation linked to my limited view of the participants' lifestyles gave me an open naivety, during initial interviews, which allowed a certain degree of freedom to see participants' experiences as lived and not immediately conceptualised. However, because my study was longitudinal in design, I also acknowledged that an intimacy of understanding would build between myself and participants, with a resultant likelihood of pre-supposition. In order to bridle any distorting pre-understandings, I attempted to follow the advice of Ashworth (1996, cited in Finlay, 2009, 12) who suggests that three presuppositions need to be set aside; these are: *"(i) scientific theories, knowledge and explanation; (ii) truth or falsity of claims being made by participant; and (iii) personal views and experiences of researchers which would cloud descriptions of the phenomenon itself"*.

As Ashworth argues (1996, cited in Finlay, 2009), it is not the role of the phenomenological researcher to argue the truth or falsity of the participants' narratives, but to take what they say as "that" which is being offered. However, that did not mean that I was a neutral observer. As we (researcher and participant) got to know each other, the circle of understanding would grow between us, fore-projections would be revised and differing points of view created. This was not a hindrance to understanding, but rather an acknowledgment that all research interviews are co-constructed, born out of the interactions and space created by the researcher and the interviewee. Crucially, as long

as I maintained a self-awareness of this issue and used bridling, i.e. restraining of one's own pre-understandings, so that a phenomenon is allowed to reveal itself (Dahlberg et al., 2008), I felt I could do no more.

1.6 A Longitudinal Approach

I decided to undertake a longitudinal approach as I wanted to present the journeyed experiences of participants over a one year period with SAP. In this way I hoped to gain a more detailed understanding of their temporal experiences and how these were influenced by a deterioration or improvement in their condition, any treatment regimen undertaken, set against seasonal duties on the farm. As Griffin and Bengry-Howell (2008) state, such an approach helps to illuminate the diverse as well as contradictory complexities of lived experiences.

By repeating semi-structured interviews along three time points over a 12 month period I also hoped to clarify initial interpretations and follow up any important strands of experience in more detail.

1.7 Structure of the Thesis

This thesis is presented in eleven chapters. The following is an overview of each:

1.7.1 Chapter Two: BACKGROUND

In this chapter, I provide contextualising information about Herefordshire, its farming tradition and the state of farming and healthcare, during 2011, the year of the study. I also explore issues related to current healthcare delivery, with consideration given to patient-led care and lifeworld-led care, relating my discussion to cardiac rehabilitation.

1.7.2 Chapter Three: A REVIEW OF THE LITERATURE

This chapter is divided into two sections. The first is a detailed review of SAP and its management, including the impact of heart disease on dyadic health, wellbeing and coping. The second section deals with the literature related to rural/farming health issues and distress. From this review of the literature, gaps in existing knowledge are extrapolated, supporting the importance of this study.

1.7.3 Chapter Four: RESEARCH PARADIGM AND PHILOSOPHY

The Farm Angina Project utilises qualitative research, seated within an interpretivist epistemology and ontological approach, namely hermeneutic phenomenology. Chapter Four provides an overview of the research paradigm and philosophy underpinning this study's methodology, including a brief history of phenomenology and the development of the lifeworld concept.

1.7.4 Chapter Five: METHODOLOGY

Chapter Five includes details of the methodology, bridging both philosophy and methods adopted by this study. Issues related the crossover between phenomenology and pain / illness, cultural factors and existential mood are discussed. An outline is then provided of how a hermeneutic phenomenological methodology shaped my practical approach, including decisions related to its longitudinal design.

1.7.5 Chapter Six: METHODS

In this chapter, I describe the methods used to undertake the Farm Angina Project and my reasons for employing them. I explore the relationship between the philosophical and methodological considerations underpinning these methods. How I undertook fieldwork is also detailed. This chapter includes a review of sampling techniques

utilised and inclusion criteria; recruitment of participants; data collection methods; ethical issues, including safety concerns and confidentiality; trustworthiness and rigour; and finally how the data were analysed.

1.7.6 Chapter Seven: FINDINGS

The aim of this chapter is to situate my participants to the reader and introduce their angina journey's as a descriptive narrative. This chapter is in three sections. The first precludes diagnosis; its aim is to evidence the subtle changes in respective lifeworlds which increasing symptoms of chest pain caused farming couples. The second section of this findings chapter provides a rich, descriptive account of male farmers' experiences of SAP, as well as the experiences of their partners. The final section describes the experiences of participants after the successful treatment for SAP. Again, I detail the differing existential journeys that members of a farming dyad took. I consider within it why, as some men found their health and wellbeing improved, a number of the female partners saw theirs deteriorate.

1.7.7 Chapter Eight: DISCUSSION, PART ONE: MAJOR FINDINGS

The aim of this chapter is to discuss the major findings of the Farm Angina Project. These are divided in to three phenomena and each is discussed in turn. They are, (i) Farming dyads existential lifeworlds were individually disrupted by the introduction of illness in the male partner. (ii) Both partners suffered an erosion of existential trust, due to the disruption in their respective lifeworld's that illness and the perceived, potential loss of freedom caused. Finally, (iii) healthcare practices did not acknowledge individual participants' lifeworld needs related to SAP; in some cases, dehumanising care was contributory to dyads' continued existential suffering

1.7.8 Chapter Nine: DISCUSSION PART TWO: INFORMING HEALTHCARE

In Chapter Nine I consider how my findings could underpin an effective SAP rehabilitation programme for farming dyads, concentrating upon a lifeworld-led care approach; incorporating phenomenological self-reflection, open negotiation between dyads, and support of vulnerability and freedom, dignity and trust.

1.7.9 Chapter Ten: RECOMMENDATIONS AND CONCLUSION

In this chapter I summarise why and how this thesis was developed and undertaken and I re-iterate the main findings. Strengths and limitations of the study are then outlined, with recommendations for further investigation. A review of the study's local and national sphere of influence to-date are given. To conclude, and in line with a hermeneutic phenomenological approach, I reflect upon my own transformative journey undertaking this research.

1.8 Use of Poetic Representation and Photographs

As a way of acknowledging the centrality of the men and women in this study, I have included creative, poetic re-presentations at the start of each chapter. This includes photographs I took of the old and new livestock markets in Hereford, during 2011, direct quotation from narratives, as well as my own re-interpretation as Senryu verse. Senryu is a short poetic form which focuses upon people and moments within their lifeworld. Senryu is similar to Haiku. Like traditional three line Haiku it consists of 17 syllables or less, (typically 5 on the first line, 7 on the second and 5 on the third) but focuses upon human experience, which Haiku does not. By limiting the writer, Senryu can intensify emotion and its ability to touch us.

Using poetry as a re-presentation of data has grown in popularity within qualitative research, increasingly seen as an “*expressive and creative opportunity for approaching knowledge-building beyond merely reducing the fullness of reality into bits and pieces*” (Szto et al., 2005, 154). Galvin and Todres (2013, 151) discuss the use of poetry as a tool within a more aesthetic form of phenomenology, an approach less concerned with summated “lifeless” qualitative research findings, but rather one that “*emphasises the textures of experience by using directional or ‘pointing’ language that evokes the experience*”. In this way, suggest the authors, knowledge is produced not only for the “*head*”, but also the “*heart*”.

I considered the use of poetry to ensure that the participants’ voices remained in the foreground and that they were not completely “*submerged*” by my words (Ward, 2011). Creating these pieces also helped me, as hermeneutic phenomenological researcher, to dwell with my data and view them openly, from a different perspective. These poetic representations exist then to help situate the reader within the participants’ lifeworld and to hear their voices above my own. They also provide an example of one way in which I manipulated my data to help uncover experiential meaning.

The photographs used throughout the thesis were taken at three time points during 2011, the year of my fieldwork. These include (i) one of the last farmers markets at the old site in Hereford city centre; (ii) the old livestock market standing derelict; and finally (iii) during one of the first market trading days, at its new home, on the outskirts of the city. Together these are a pictorial record of one aspect of change to farming life in Herefordshire at the time of the study.

1.9 Summary of the Chapter

The aim of Chapter One is to give an overview of my reasons for undertaking this research and to provide contextualising information as to its relevance. Within it, I have also outlined the study question. I

have discussed my reasons for selecting a hermeneutic phenomenological approach and, in keeping with this perspective, have highlighted my pre-understandings.

According to Wojnar and Swanson (2007) hermeneutic phenomenology is a research methodology useful for describing human experience in relation to historical, social and political forces that shape meaning of wellness, illness and personhood. It is therefore well placed to answer “*what*” and “*how*” questions about human issues within these contexts (Whitehead, 2004). It was through this perspective that I chose a longitudinal hermeneutic phenomenological approach to investigate couples belonging to Herefordshire’s farming community who were experiencing SAP. This decision was taken over other types of phenomenological enquiry, such as Giorgi’s (2009) descriptive phenomenological method, which advocates bracketing out the socio-cultural “*outer world*” as well as the researcher’s individual biases in the formulation of data and its analysis; or IPA (Smith et al., 2009), which does not acknowledge enough the effect of a researcher upon data collection and its subsequent analysis, in my opinion. I found I was unable to accept either standpoint in relation to my own research, preferring instead to be guided by those advocating the virtues of hermeneutic phenomenological enquiry, which I will detail in chapter five.

This chapter also gives an overview of subsequent chapters included in this thesis, in order to help the reader orientate themselves to the study. To conclude, I give my reasoning for the inclusion of poetic representations of the data within this thesis.

In the next chapter, I provide contextualising information about Herefordshire, its farming tradition and the state of farming and healthcare, during 2011, the year of the study. I also provide an overview of current issues related to participation in cardiac rehabilitation in the UK and explore relevant theoretical considerations related to how care is delivered.

Chapter Two: BACKGROUND

“heavy winter feed
wheelbarrow frozen to grip
i lower torn skin”



“Now Christmas day was serious because I er, it was frosty and, and them two fingers there and them two, because I’ve got arthritis I’ve got to have my fingers out in the gloves you know and they stuck to the wheelbarrow and I had all new skin and I couldn’t eat, erm, dinner on Christmas day because it had all come off...oh it was a hard winter here ...”

Molly

2. Chapter Two: BACKGROUND

2.1 Introduction

The aim of this chapter is to provide the reader with relevant contextual information pertaining to the environment and time-period in which this study was undertaken. Firstly, I shall give an overview of the county of Herefordshire, its farming tradition and the state of farming and healthcare, during 2011, the year of the study, before providing a review of current issues related to participation in cardiac rehabilitation, in the UK. This information will then be linked to wider healthcare delivery considerations, including patient-centred care (PCC), lifeworld-led care (LLC) and the cultural competency of each. I have included this latter section because issues relating to healthcare delivery (in addition to the informational content of such programmes) were highlighted as a prominent concern, during data collection. This will also assist the reader in recognising the breadth and complexity involved when planning a locally directed SAP rehabilitation programme.

2.2 An Overview of Herefordshire

The year 2011 saw a number of changes within farming, as well as healthcare provision in the area. It was against this backdrop that the Farm Angina Project was derived.

Herefordshire is a predominantly rural county of 842 square miles, situated in the south-west corner of the West Midlands region bordering Wales. The city of Hereford is the centre of the county for employment, administration, health, education facilities and shopping, etc. The other principal locations are the five market towns of Leominster, Ross-on-Wye, Ledbury, Bromyard and Kington (Herefordshire Council, 2009).

In 2007 (the last time it was recorded), Herefordshire had a total resident population of 178,400 (Office of National Statistics, 2007). Herefordshire has an older age profile than both England and Wales, overall. Conversely, less than a third (31%) of Herefordshire's population is under 30, compared to 37% in England and Wales as a whole and 38% within the West Midlands (Herefordshire Council, 2009). This is a scattered population across a wide rural area, which presents particular challenges for service delivery within the county. Sparsity measures give an indication of how widely dispersed an area's population is, with 25% of Herefordshire's population recorded as living in a "very sparse" area, the highest figures in England (Herefordshire Council, 2009).

More than 54% of the population of Herefordshire lives in rural areas, whereas for England as a whole the rural population is approximately 18% (HPCT, 2008). The employment structure for Herefordshire shows that there are just under 68,000 people in non-agricultural employment and 11,000 in agricultural employment (Herefordshire Council, 2009). Migrant workers are increasingly being employed in the agricultural sector, followed by the food processing industry. Of these, it is estimated that approximately 8,000 workers are employed, each year, on farms within the County (HPCT, 2008). In 2007, the majority of agricultural land in Herefordshire was either permanent grassland (43%) or cropping (including bare fallow 37%).

Compared to both the West Midlands region and England, as a whole, Herefordshire has significantly lower total mortality rates. However, the observed death rate from skin cancers, accidents, stroke (particularly in women) and suicides is higher than the national average; this can be partly attributed to the predominance of agricultural work in the county, to which the first three causes are linked (HPCT, 2008).

Mortality rates from circulatory diseases include deaths from diseases such as coronary heart disease and strokes. In Herefordshire, these mortality rates have been steadily decreasing. In 2004-06, rates for

Herefordshire (72.5 per 100,000) were lower than both the West Midlands Region (90.7) and England (84.2) (Herefordshire Council, 2009). However, the specific number of angina sufferers in the county is not known.

2.2.1 Herefordshire's farming tradition

Farming in Herefordshire dates back to Neolithic times and throughout the centuries has had a reputation for its diversity, which remains, even to this day (Evans et al., 2001). Significantly, three processes of industrialisation have had an effect on farming practices in Herefordshire (Evans et al., 2001). These are: (i) Intensification – this was the move to increase output from farms. It involved capital investment into businesses around farming, to improve and increase the delivery of products and farming operations. Intensification also included the mechanisation and automation of product processes and the application of biotechnology; (ii) Concentration – is the trend towards fewer but larger farms *“whereby a proportion of farmers cease to farm, whilst others enlarge their landholding in search of production economies of scale”* (Evans et al., 2001, 12). Evans et al., (2001) suggest that having fewer farmers on larger farms has led to social changes within the countryside and an increase in non-farming rural dwellers. It has also generated inequalities between neighbouring farmers, in terms of income and farm size. Finally, (iii) Specialisation – this entails farmers eliminating their least profitable enterprises, in order to focus upon one or two more profitable endeavours. Evans et al. (2001) argue that this has caused some structural rigidity to farming, whereby farmers are less able to switch production to another form of farming, primarily due to the large amounts invested in modern production systems.

Traditionally, the main farming in Herefordshire was rich species grassland to feed livestock, native Herefordshire cattle breeding and hop farming (Evans et al., 2001). However, over the last decade (due

to changes in farm practices, as listed), there has been a decrease in hop production while, at the same time, a rise in potato and apple production. Apple and pear production is supported by county-based processing companies such as H.P. Bulmers, and H. Weston and Sons Ltd., both of which have contracts with local farmers to supply fruit for their large scale cider production (Evans et al., 2001).

The pressure on farm incomes has led farmers to diversify within farming, but also “*to seek non-agricultural forms of income generation, based on or off the farm*” (Evans et al., 2001, 29). Both diversification and non-agricultural employment are collectively known as pluriactivity. Pluriactivity within Herefordshire has centred on the provision of farm-based accommodation; farm-based recreation, such as riding, shooting, fishing, motorsports; as well as farm education programmes, such as farm work opportunities, pets’ corner and farm tours. Farmers have also sought to add value to their products through on-site processing operations, including cheese and ice-cream making, as well as selling “pick-your-own” fruit through a farm shop.

In keeping with other counties over the last decade, there has been a decline in agricultural production in Herefordshire. The reason for this decrease is unclear, although the continued pressures upon farmers for agricultural business adjustment, a general decline in profitability of farm businesses, alongside mounting development demands to meet the needs of a growing population are all possible factors (Evans et al., 2001).

There has been a general decline in the number of agricultural holdings in the county, “*explained by the process of concentration*” (Evans et al., 2001, 12). This has also seen an increase in the proportion of solely owned farms, rather than part-owned or rented properties.

Despite this growth in the size of Herefordshire farms, the agricultural labour force has slowly decreased, particularly in whole-time workers; in 2001, there was an average of one full-time position for every 2.5 farms in Herefordshire (Evans et al., 2001, 16). Evans et al., (2001, 17) argue

that this suggests that farming in Herefordshire is becoming more family-labour oriented, due to part-time farming and diversification, which puts a strain on *“family forms of agricultural business labour under pressure for business survival”*.

In a survey of 209 Herefordshire farmers, White et al. (2005, xii) compared the results of an earlier study looking at the state of the industry in the county (Evans et al., 2001). The authors of the survey state that the biggest change noted in respondents, between the two studies, was an increase in depression, apathy, family break-ups and suicide, due to financial issues and perceived lack of government support.

The second study followed the outbreak of the foot and mouth disease (FMD), in 2001. Although the county remained one of the less affected areas, specific areas within Herefordshire were among the worst hit (White et al., 2005); 42 farms were directly affected by the disease, but *“hundreds of farms lost stock due to contagious and non-contagious contact as well as slaughter on suspicion”* (White et al., 2005, 9). This involved all livestock, mainly sheep and lambs (88.4%), but also cattle, pigs and goats (White et al., 2005).

White et al. (2005, 11) argue that FMD was a *“blip”* in a general downward trend of profitability for Herefordshire farmers. They cite a number of other factors that have affected the profitability of farms in Herefordshire, including lower milk prices, falling income from arable, apples and potatoes and the rising cost of sheep.

2.2.2 Farming in Herefordshire 2011

It is important within hermeneutic phenomenological research to describe the context in which the study was undertaken and hence the need in these final two sections to outline what the year 2011 was relevant for, with regards to farming in Herefordshire and healthcare provision in the region.

Three aspects of 2011 stood out, from a farming perspective; it was the coldest December on record; the livestock market in the middle of Hereford City relocated; and there were concerns regarding the spread of bovine Tuberculosis (TB), Blue Tongue and the Schmallenberg virus.

The extremely cold winter which farmers had to endure from the start of November 2010 to February 2011 left a number of them stranded and cut off on their farms. Indeed, the Met Office (2011) reported that it was the coldest December since records began. The rest of 2011 saw the warmest April on record and a relatively dry rest of the year, with rainfall only half the average within the Midlands (Met Office, 2012). Winter 2012 was also much milder than the year before (Met Office, 2012).

Having been situated in the middle of Hereford for around 150 years, the Farmers Livestock Market was moved to new premises on the outskirts of the city. The move was welcomed and criticised in equal measure. Concerns from local traders in Hereford city centre that it would affect business appeared well founded. However, improved access offered to farmers and their vehicles by the new market in Stretton Sugwas saw a rise in stock trade. Between June and November 2011, 136,000 animals were sold, compared with 115,000 in the whole of 2010 (BBC Hereford & Worcester, 2011).

Herefordshire was the third highest county to be affected by bovine TB in 2010, with 2,696 of cattle slaughtered (Hawkins, 2012). Ongoing concerns regarding potential badger vaccinations and culling were evidenced during discussions with the farmers, in 2011. Towards the end of 2011, a new threat to animal welfare began to emerge. This was the impending arrival of two diseases called Blue Tongue and the Schmallenberg virus, both spread by infected midges blown over from the continent (Gregory, 2012). All three diseases caused concern within Herefordshire, during the year of data collection.

2.2.3 Healthcare in Herefordshire 2011

The year 2011 saw major re-organisation in the running and delivery of health and social services within Herefordshire. Hereford Hospital's National Health Service (NHS) Trust and Herefordshire Primary Care Trust were replaced by the Wye Valley NHS Trust. This was an amalgamation of acute hospital and community healthcare, as well as adult social services, previously held by Herefordshire Council. Herefordshire was the first region to undertake such integration within the UK (Hereford Hospitals NHS Trust, 2010/11). As part of this process, the new organisation listed its aims and new methods of working (Hereford Hospitals NHS Trust, 2010/11, 17), as follows:

- promoting healthy lifestyles, wellbeing and independence;
- self-care and screening;
- pro-active support, instead of reactive care;
- working with neighbourhoods, outside traditional hospital settings;
- health and social care professionals working together; and
- hospital provision for those who need it.

Certainly, this research study fitted with the ethos being promoted by Wye Valley NHS Trust, in 2011, particularly in regard to wanting to work more closely with neighbourhoods outside traditional hospital settings.

As part of this major restructuring of services was the introduction of the "Care Closer to Home" initiative. Neighbourhood teams of health and social care professionals were established in January 2011, their aim being to provide care packages in the community, so that patients could remain at home while receiving care, or be discharged more quickly after hospital admission (Wye Valley NHS Trust, 2011).

Cardiac Services within Herefordshire in 2011 were based at Hereford County Hospital. These services consisted of the Cardiology Doctors, Inpatient Coronary Care Unit and Ward, Cardiac Investigations Department, including a Diagnostic Angiography Suite, Cardiac Rehabilitation and Heart Failure Services (Cardiac Services, 2011).

Although the Cardiologists were able to carry out investigatory angiograms to ascertain the patency (or degree of narrowing due to atherosclerosis) of coronary vessels, in Hereford; they were unable to perform interventions, such as stent insertion (i.e. the placing of a metal frame within the artery to increase its diameter), or more radical heart surgery. Up until 2010, patients were usually referred to the Queen Elizabeth Hospital (QEH), in Birmingham, if they had suffered a heart attack or required elective interventions. However, in 2010, an arrangement whereby patients could be seen at Worcester Royal Hospital (WRH) for stent insertion was agreed. The aim was to reduce the time taken from myocardial infarction (due to a blocked coronary artery) to reperfusion (the unblocking of a coronary artery), an important determinant of survival and heart muscle damage severity (NICE, 2013); which, in 2010, was recorded as longer than the national average for those suffering heart attacks, in Herefordshire (South East Public Health Observatory, 2011). In 2010-11, the service was still not 24-hour, which was its final intention (NHS Improvement, 2012). However, this meant that Herefordshire SAP sufferers requiring an elective admission for stent insertion were now likely to be referred to WRH. Indeed, during the study, a mix of participants who had undergone an angiogram in Hereford and then stents in Worcester or surgery at the QEH were seen. At this time, CR was accepting people who had undergone stents for SAP on to its programme. However, no dedicated SAP specific programme was available, despite a national call for its implementation (NACR, 2008).

Evident from this review is that during 2011, the cardiac care a person living in Herefordshire may receive could well be spread across three Counties. This has obvious travel and time consequences for patients and their families; the QEH, Birmingham being over 70 miles and one and half hours' drive time from Ewyas Harold, on the western fringes of the County.

2.3 Participation in and Delivery of Cardiac Rehabilitation

CR is defined as a *“process by which people with cardiac disease, in partnership with a multidisciplinary team of health professionals, are encouraged and supported to achieve and maintain optimal physical and psychosocial health”* (NICE 2011, 15). It has been identified that participation in CR remains low, with between only 24% (De Angelis et al., 2008) to 35% choosing to start rehabilitation (Mosleh et al., 2009) and as few as 22.5% completing the course (Harrison and Wardle, 2005).

In a recent, sizeable qualitative systematic review, Clark et al. (2012) investigated the influences on attendance at CR, after referral. Ninety studies undertaken in the USA, UK, and Canada, Australia, as well as a number of other European countries, were included. The authors concluded that decisions to attend CR were influenced more by social factors than by health professionals' advice or clinical information. The authors listed a number of barriers to attendance.

Personal barriers to attendance included:

- low insight and knowledge into services – the programme would be not appropriate or beneficial to people “like them”;
- perceptions about heart disease – attempting to reduce the risk of further heart problems was deemed futile, as participants expressed a low sense of control over their future health;
- negative views of services/health systems – impacted upon their decisions to attend and included having poor or culturally insensitive communication; attendance could also be limited because no local service was offered;
- self and identity – participants did not attend when they saw themselves as different from the types of people who should attend CR; based on their sense of identity, patients viewed the services as not needed, unlikely to be of benefit for “old people”, or conflicting with their priorities; and

- financial and work constraints – participants reported attendance had financial ramifications which could influence attendance.

Contextual barriers to attendance included long travel distances to CR programmes, particularly from rural settings or where transport links were poor; and lack of support from family, through over-protecting behaviours, demands for care giving, or other family commitments.

Clark et al. (2012, 840) state:

“Interventions are thus needed that supplement programs to promote CR attendance and draw on evidence, as is detailed here, on the social and contextual factors that actually influence attendance in representative patient groups.”

They argue further that:

“Attendance in CR is influenced by a range of psychosocial, familial, and contextual factors. Future interventions to promote higher access should include family members and foster patients' sense of control of cardiovascular risk, harness similarities rather than differences with patients who participate, and harness family members to support rather than curtail attendance. Peer support of both patients and families may be a particularly promising and efficient means to facilitate these aims” (Clark et al., 2012, 841).

A number of other studies have looked to assess the take-up of CR within rural areas. Harrison and Wardle (2005) surveyed 236 patients living in South Staffordshire, and found that a number of factors were linked to low utilisation: age over 60 years, being female, and access to services (including problems with public transport, parking, and the time and location of classes). De Angelis et al. (2008) explored attendance at rural Australian CR programmes. They also found that distance from home to the programme venue was a key barrier to attendance. Importantly, the authors qualified the distances involved, finding that those attending often lived an average of 15.4 km (9 miles) away, whereas “non-attenders” lived an average of 40.4km (25 miles) from the

programme. Ease of access to transport was another important factor in enabling attendance.

King et al. (2006) undertook a series of grounded theory studies, the aims of which were to describe and explain how gender and ethno-cultural factors influenced people's lifestyle change choices, when faced with coronary heart disease. Part of their findings highlighted how the "work of today" took priority over seeking healthcare services, or attending CR, for rural-living and working participants, such as farmers. *"Even rural females believed that the work of the farm had to take precedence over their health-related choices"* (King et al., 2006; 1098).

In the next section, I shall introduce issues related to the delivery of patient services. This will include a brief review of patient-centred care (PCC), lifeworld-led care (LLC) and the need for cultural competency in both. My reason for focussing upon these two topical and relevant approaches is because both are credited with being more sensitive to the individual needs and values of patients. It is argued that this helps to assuage some of the personal and contextual barriers that hinder effective healthcare, through targeted, respectful support and empowerment (Morgan and Yoder, 2012; Galvin and Todres, 2013).

2.4 Consideration of Approach to Care

The recent conclusions of the Francis Report into the failings at the Mid Staffordshire Foundation Trust (Francis, 2013) have led to criticisms that current NHS services put pressure on those who work within them to relinquish personal responsibility, in favour of third person *"artificial person"* roles where policy and process become more important than compassionate, personalised care (Soundy and Roskell, 2013). The Report states (Francis, 2013, 83):

"It is not the system itself which will ensure that the patient is put first day in and day out. It is the people working in the health service and

those charged with developing healthcare policy that need to ensure that this is the case.”

There appears, then, a pressing need to consider not only how services are shaped to better meet the needs of individual patients, but also how healthcare workers approach those under their charge.

Hanlon et al. (2011) argue that a new wave of health initiatives is necessary, in order to tackle emergent issues related to health and wellbeing, in 21st century UK. The authors suggest that there have been four previous public health waves, based on historical data, outlined in table 1:

The first wave	The second wave	The third wave	The fourth wave
<p>Approximately 1830-1900:</p> <p>Birth of civil engineering and great public works. Introduction of the early appliance of science to social medicine; large scale public health interventions, e.g. water and sanitation. Growing concern regarding social problems.</p>	<p>Approximately 1890-1950:</p> <p>Scientific rationalism leads to breakthroughs in medicine and germ based theories of disease. Health associated with perception of body as machine – able to be fixed by the right “expert” in a particular field.</p>	<p>Approximately 1940-1980:</p> <p>Emergence of the welfare state. Health seen as the result of conditions of everyday life. Setting up of NHS, social security, universal education.</p>	<p>Approximately 1960-2000:</p> <p>Effective healthcare interventions helping to prolong life. Risk factors and lifestyle become central concern to public health related to major disease patterns such as diet, exercise, tobacco, alcohol, illegal drugs.</p>

Table 1: A table outlining the history of public health waves (Hanlon et al., 2011)

Hanlon et al. (2011) question what the defining qualities of the next and fifth wave of emerging public health strategies will be, based on their

assessment that current strategies will not prevail in tackling such issues as the rise in obesity, health inequality and deterioration in wellbeing. The authors argue that the legacy of a biomechanical approach to health, born of the four waves and the idea that a cure can be found for every disease, is failing, as we see “*diminishing returns from formerly successful approaches*” and as a rise in new patterns of illness are born out of the “*pressure cooker lifestyles*” of 21st century industrialised living, e.g. depression. The authors blame this partly on the fact that “*another key characteristic of the four earlier waves of public health intervention is the relative unimportance of the individual and the human spirit*” (Hanlon et al., 2011, 34)

Certainly, existing CR programmes have been criticised as being increasingly the product of new century “healthism”, in which they offer “off the peg” lifestyle choices constructed and understood in terms of known cardiac risk factors and how these should be tackled, clinically (Cheek, 2008). Furthermore, Cheek (2008) argues that a discourse of “*performativity*” has permeated and transformed health rhetoric. CR offers both the incentives, rewards, changes and promises, but also sanctions based on such a standpoint, namely one that encourages the individual to be responsible for his own health and lifestyle choices, but within a narrow range of options; one that marginalises those who find its path too restrictive, or difficult to adapt to their current way of life. Herefordshire CR during this period offered only a group-based programme based on a formula of aerobic exercise, relaxation therapy and general healthcare advice, presented over an eight week period. No accommodation to those unable to attend a day time appointment was given, although three venues were offered across the County. One might construe that this service arrangement might be too restrictive for the Counties farming community.

There is criticism of CR’s seeming intransigence to view itself from any other perspective than that of a positivist approach which, according to Clark et al. (2007), limits its scope to grow more sensitive to need. The authors argue that many heart health programmes are based on core

positivist assumptions that lack focus on the unobservable phenomena, and rely rather on *“impoverished conceptions of the social, contextual, and personal”*, propped up by a *“narrow body of empirical evidence”* (Clark et al., 2007, 517). Crysanthou (2002) terms this the *“age of healthism”* and a *“somatopia”* – where individualised body health is its focus. Lost from this is a regard of the wider social landscape and how people and their health fits within these:

“Care of the self is not necessarily at odds with a wider social and environmental concern but an exaggerated degree of self-absorption obscures the need for an ecological, holistic and political strategy of health. By disregarding this wider philosophical and social landscape, the utopian body paradoxically loses sight and control of factors that undermine its most concerted efforts to attain and maintain health” (Chrysanthou, 2002, 477).

Not all agree with this viewpoint. Wheatly (2005, 456), for example, does not accept this argument, countering that patients are not repressed during CR; rather, they are *“enabled by disciplinary power”*. She observed the positivity that such programmes can bring via their directed approach, not only through physical transformations, but also the fun, camaraderie and improved self confidence that is fostered within. She concludes that *“the bodily and social changes enabled and affected by their participation in cardiac rehabilitation are evidence of the productive possibilities of disciplinary power”* (Wheatly, 2005, 456). However, it should be noted that Wheatly only observed those who had decided to attend CR and who, one could argue, had already bought into the programme’s ethos.

Returning to Hemingway (2011, 3), the author states: *“... how we begin to understand our human experience of the world and how we enable each other to flourish has been markedly lacking from the previous four waves”*. Here, the author argues that the *“four waves have resulted in a negative micro measurement approach”* to health intervention which focuses on the individual biology or behaviour, rather than arguably

more influential macro influences on wellbeing, such as social, welfare and economic issues (Hemingway, 2011, 3). This, she argues, means wellbeing is not being addressed. Hanlon et al. (2011) conclude that the fifth wave is not in conflict with its earlier counterparts; rather, it builds upon them, so that it can eventually move beyond their endpoints. Patient-Centred Care (PCC), is seen by some as the starting point of this new wave; it is a term which has grown in popularity over the last two decades, associated as it is with hope of improved quality of care and potential for better health outcomes (Jayadevappa and Chhatre, 2011; McMillan et al., 2013).

2.4.1 Patient-centred care

PCC has a number of definitions; however, it is generally described “*as an approach to care that meets the specific needs, values and beliefs of patients*” (McMillan et al., 2013, 568). Morgan and Yoder (2012, 9-10) have developed a model underpinned by the four key attributes most frequently associated with PCC, following their review of the literature; these attributes are as follows: (i) Holistic Care – in which the impact of illness is recognised in terms of how it affects the entire person, and their subsequent multifaceted needs. Such care takes into consideration not only the physical, cognitive, psychological and behavioural elements of the person, but also their situational, family, cultural and religious needs. (ii) Individualised Care – this is the most frequently referenced element of PCC and is seen as a consideration of the individual’s unique needs, preferences, and personality and health concerns, as key to individualised care planning. (iii) Respectful Care – recognises individuals as active, competent decision makers about their own care, by respecting individuality and supporting the person’s strengths and abilities, so that they remain free to choose during their care journey. Finally, (iv) Empowering Care – encourages autonomy, self-confidence and determination, through supported participation in healthcare decision making. Such an approach consists of assisting

the individual to obtain information and learn, so that they make informed choices, gain effective communication skills and ultimately feel empowered towards contributing to their own healthcare decisions.

McMillan et al. (2013), argue that the concept of PCC, and understanding regarding approach remains elusive, hidden behind interchangeable terminology that is interpreted differently, across health professions, leading to confusion when attempting to action in a practical sense. McMillan et al. (2013) undertook a systematic review of randomised controlled trials pertaining to PCC and concluded that, although PCC shows promise regarding improved patient emotional wellbeing, PCC as a model of care has not yet been shown to impact on clinical and functional outcomes. However, the authors did consider that the literature demonstrated PCC to be an effective intervention for improving health professionals' communication skills and their ability to bring patients into the decision-making process.

PCC, however, has its detractors. Plinick and Dingwall (2011, 1379), for instance, argue that;

“The drive towards patient-centred medicine rests partly on the conceptualisation of medicine as some kind of personal service or product, accessed as a result of an individual decision about purchase or usage. The problem is that physicians do not behave like sellers in a market, deferring to customer demand”.

The authors suggest a sociological view that sees medicine in disciplinary terms exerting order as control agents for the management of social deviance, as partly the reason for this asymmetry. Moreover, the doctor's aim is not just to heal the sick, as the PCC model assumes, but to adjudicate on contestable claims of dependency. Hence the asymmetry is born from a social hierarchy required for the doctor to do his duty, embedded as it is *“within a wider functionality of the institution of medicine in society”* (Plinick and Dingwall, 2001, 1381). Arguably, then, the remit for PCC may lie with those allied to the medical profession, such as nurses and physiotherapists, rather than with the

doctors themselves. These healthcare professionals could act as conduits between the lifeworld of the patient and the medical world of the doctor.

From an altogether different viewpoint, Galvin and Todres (2013, 37) are critical of the “medical model” of PCC, that has “*over-emphasised illness and professional authority*” and are suspicious of patient-led approaches now emanating from the same source. They argue that the focus on improved patient agency and self-authority has not taken sufficient account of the existential meanings of suffering and wellbeing. As such, these consumerist/citizenship models do not consider when a person is unable to champion their own needs, when they are “*exposed*” and “*vulnerable*”. The authors conclude: “*...when people become patients they want to be seen in both their agency and vulnerability and feel unmet by interactions that emphasise one or the other*” (Galvin and Todres, 2013, 37).

Hanlon et al. (2011) suggest that elements of this proposed fifth wave can be found in the positive psychology movement. They argue that, for humans to survive as a species and grow in complexity they must re-engage with what it means to be “human”.

“*This will involve rediscovering a reward system beyond the material as the comfortable environments that we have created, believing that this will improve our lives, now undermine the essence of what makes life worth living*” (Hanlon et al., 2011, 34).

Hemingway (2011, 6) poses the question: “*How can we promote wellbeing freedoms within and across communities, without knowing what it is like in human terms to live there?*”. She argues that a more humanistic approach is now required, that steers away from “*the ‘cookie cutter’ one size fits all approach to prevention which dissociates the individual from their social determinants of health and, crucially, the context of their life*” (Hemingway, 2012, 450). Hemingway advocates the development of a lifeworld approach to patient care, alongside existing systems.

It is not unreasonable to suggest that PCC could offer a way of better understanding and serving the hidden, agricultural communities of Herefordshire, beyond medical treatment protocols already in use. Incorporating a lifeworld-led approach may also help to sensitively tailor care, supporting both individual agency and vulnerability during illness on the farm. I will now consider this approach in more detail.

2.4.2 Lifeworld-led care

Galvin and Todres (2013, 36) suggest that lifeworld-led care (LLC) is different from PCC, although the former can “*deepen an understanding of what patient-led care can mean*”. LLC is more than just giving the patient “a voice”; it is about acknowledging that people experience both freedom and vulnerability, as they traverse illness, and supporting this movement within their existential wellbeing, above the more restrictive pursuit of absence of illness only. Through existential acknowledgment, the authors argue that a patient’s vulnerabilities, as well as possibilities, are more deeply met. They are not just consumers competing for care, but “storied beings” with specific suffering-wellbeing trajectories, within which there are strengths and weaknesses that the informed practitioner can work with, for the benefit of the patient. Key to Galvin and Todres’s approach is the need to gain an insider perspective of a person’s lifeworld as foundational to any act of caring. The authors argue that by learning “what it is like” for a person helps to guide a more humanised care approach (Todres et al., 2014).

The authors argue that healthcare professionals should attempt to reach out towards insiderness, exchanging self with the other individual, to try and imagine how they would think, feel, act in the same situation. “*The appreciation of insiderness has within it a concern for the well-being of the patient and this constitutes a caring power*” (Todres et al., 2014, 7). According to the authors, this “*not knowing*” the other’s life can create a guardedness in the health professional and fall-back towards an interventionist attitude, in order to assuage their own

anxieties. Although it is argued that healthcare workers develop generic cultural competencies, in order to deal with a wide variety of patients (Papadopoulos, 2006), one could argue that this might limit the degree of “insiderness” when engaged with someone from another culture. Recognising the need for a degree of cultural competency is, therefore, also a necessary constituent of PCC and LLC.

2.4.3 Cultural competency

Contingent on both PCC and LLC is a striving for cultural competency. According to Vaughn et al. (2009, 65), behind health behaviour is attribution – *“the causal explanation processes used to understand the world”*. They assert that people from diverse cultural backgrounds make different attributions. This means that people will approach health, illness and its management from a number of convergent, as well as divergent, perspectives. Buse et al. (2013, 15) argue that experiences of trauma transcend cultural differences; however, culture does affect how it is interpreted and how it is managed. The authors state that *“multicultural competency among rehabilitation counsellors is essential”* (Buse et al., 2013) to deal with this reality. Buse et al. (2013, 19) recommend that therapists remain attentive to the expressed needs of clients, *“rather than making assumptions about ... specific needs or deficits”*, in this way, helping clients to draw upon resources from within their own world to effect beneficial resilience to trauma. The authors also argue that, by disregarding the wider socio-political context in which a person lives, healthcare professionals can *“mistakenly portray the individual as a solitary agent of their suffering”* (Buse et al., 2013, 20), when they may simply be reflecting a culturally shaped position.

2.5 Summary of the Chapter

The aim of this chapter is to provide a contextualising platform for the reader, to assist them further in understanding how, why and where the

Farm Angina Project was developed. I have provided a thumbnail sketch of Herefordshire, its farming tradition and the state of farming and healthcare, during 2011. In this chapter, I have also reviewed current issues related to participation in CR, in the UK, as well as wider healthcare delivery considerations. Models of healthcare related to PCC and LLC were outlined and debate surrounding the practice of these models discussed. I have also introduced the reader to the idea of a lifeworld perspective for the first time, which is central to this thesis.

The next chapter provides a literature review of research in the field. It is divided into two sections, which reflect the main perspectives brought together during my search. The first section provides an overview of SAP, its management and review of the literature related to its experiencing by the sufferer and their partner. Evidence related to how couples cope with heart disease is also featured. In the second part of the chapter, I give an overview of health from a farming perspective, and explore how clusters of non-medical distress can affect and be impacted by illness.

Chapter Three: A REVIEW OF THE LITERATURE

“all my sheds are full
and heart made heavy by them
longs for space to beat”



“I thought this is just, this is a manifestation, a physical manifestation of a bigger problem in my life which is congestion. It’s rooms full of rubbish, sheds full of stuff that have never been sorted out, and now it’s blockages in the arteries (laughs), I just thought this is a, this is a reflection of the outside so I’ve got to mend everything and here’s my chance, I’ll change work...that’s how I’m still thinking!”

Kevin

3. Chapter Three: A REVIEW OF THE LITERATURE

*“Ah happy hills, ah pleasing shade,
Ah fields belov’d in vain
Where once my careless childhood stray’d
A stranger yet to pain”*

Thomas Gray (1747)

3.1 Introduction

This chapter is divided into two sections; the first provides an overview of SAP, its management and review of the literature related to its experiencing by the sufferer and / or partner. Evidence related to how couples cope with heart disease is also featured. The second half of the chapter provides an overview of health, from a farming perspective, and explores how clusters of non-medical distress can affect and be impacted by illness. In my conclusion, I consider how these two differing perspectives, when allied, offer a credible and important research direction, i.e. hermeneutic phenomenology, with which to understand the lived experiences of farmers with SAP and those of their partners.

This review is representative of research within the field; focussing upon outcomes and applications from key papers identified during my investigations. This approach was taken due to an early realisation that I could not locate any papers dealing, specifically, with the subject matter and patient cohort linked to my study. I would therefore have to cast the net wider than first intended, in order to gain a number of differing perspectives deemed relevant to my research goal. It was clear from the outset that I needed to look not only at angina experiences, but also at how couples cope with heart disease and health / illness specific to farming communities. This is reflected in the way I have divided the rest of this chapter.

3.2 Part One: Stable Angina Pectoris

It is reported that William Heberden first presented the malady, SAP, as it is still recognised today, to the Royal College of Physicians of London, in 1768: “... *a sense of strangling or anxiety in the chest*”, where henceforth the condition rose nearly fourfold, in the next decade, seemingly due to doctors’ newly found ability to recognise it (Michaels, 2001).

The clinical definition of SAP has grown, over the years, as more evidence is obtained pertaining to its cause. Commonly, this “*symptom term*” is defined as “*a clinical syndrome of chest pain or pressure precipitated by activities such as exercise or emotional stress which increase myocardial oxygen demand*” (SIGN, 2007, 1). SAP is caused by an imbalance between myocardial (heart muscle) oxygen supply and consumption, leading to ischaemia in the muscle, metabolic disruption and subsequent irritation of receptors in cardiac nerve endings (Fox et al., 2006). The condition is exacerbated by exertion and dissipates with rest, as blood supply and demand to cardiac muscle stabilises.

Based on epidemiology produced in the NICE Guidelines on SAP (NICE, 2011) the incidence of SAP in the UK appears to be rising, in contrast to other types of coronary artery disease. It is estimated that 2 million people in England have had SAP, it is more prevalent in men than women, and rises steeply with age. Figures from the Health Survey for England (ICHHS, 2006) suggest that approximately 8% of men and 3% of women aged 55 to 64 and around 14% of men and 8% of women aged 65 to 74 have, or have had, SAP.

3.2.1 Treatment of stable angina pectoris

De Bono (1999), for the Joint Working Party of the British Cardiac Society and Royal College of Physicians of London, undertook a review of the management of SAP. The author suggests treatment can be

considered at four levels (listed below); little has changed to this model of care, since its initial presentation in 1999:

- Risk Factor Management – dealing with underlying, controllable risk factors for coronary atheroma, i.e. smoking cessation, blood pressure control, cholesterol control through dietary and / or pharmacological means, regular exercise, and weight control.
- Pharmacological Management – mainly involving beta-blockers, calcium channel blockers, Potassium channel blockers and nitrates.
- Coronary Revascularisation – involves coronary artery bypass graft (CABG) or Percutaneous Intervention (PCI).
- Rehabilitation – deals with lifestyle modification to decrease controllable risk factors associated with CHD and provision of exercise.

There appears current controversy regarding the long-term prognostic benefit of revascularisation over the medical management of those with SAP (NICE, 2011). The treatment of SAP is undertaken mostly within primary care, by the sufferer's local General Practitioner (GP) Practice (Crilly et al., 2006). However, rehabilitative input to this group of patients remains sparse, in the UK, with most traditional CR services programmes catering only for those recovering from myocardial infarction and / or heart surgery. According the National Audit of Cardiac Rehabilitation (NACR, 2008), 4% of individuals newly diagnosed with SAP currently receive CR, compared to 38% of those recovering from MI, 55% CABG and 45% post angioplasty.

3.2.1.1 Psycho-educational intervention

According to SIGN 96 Guidelines for SAP (SIGN, 2007), psychological factors exert an influence on patients with SAP, in several ways, and should receive attention during assessment and subsequent treatment. These include fears related to limitations placed on people by SAP, which can become misconceptions about the severity of the condition,

leading to fear-avoidance behaviours. This can lead to high anxiety and / or depression in SAP sufferers.

Leading on from this, there is evidence that patients with mild to moderate SAP have significantly lower quality of life (QOL) ratings (Gravely-White et al., 2007), compared with the general population, or those with other long-term conditions, e.g. diabetes, epilepsy and asthma (Lyons et al., 1994).

Sullivan et al. (2008) undertook a large study (n=1059) of SAP sufferers and found that SAP experienced in daily life is more strongly and consistently associated with psychological distress and the personal threat associated with SAP, than with inducible myocardial ischemia. The authors suggest that such findings support SAP treatment strategies which aim to reduce threat and distress, as well as to reduce myocardial ischaemia (decreased blood flow to the heart muscle due to partial blockage of a coronary artery).

The SIGN 96 Guidelines cite Lewin et al. (2002) in their recommendation of the Angina Plan, psycho-educational intervention package aimed at correcting misconceptions and maladaptive beliefs within a broader self-management plan for SAP. The European Society of Cardiology Guidelines on the Management of Stable Angina Pectoris (2006) do not highlight the need for psychological intervention; however, they do make brief reference to it, again citing Lewin et al. (2002) in one of only two papers reviewed. They state that a diagnosis of SAP can cause anxiety and that some reassurance, relaxation and stress management may be warranted.

This reliance on the Lewin et al. (2002) paper, in both SIGN 57, SIGN 96 Guidelines, and their respective American (ACC/AHA, 1999) and European Guidelines (Fox et al., 2006) appears to demonstrate a lack of good quality evidence, with which to advocate psychological and / or cognitive-behavioural intervention, as part of SAP management. On close inspection of the Lewin et al. (2002) paper, there would appear to be a number of flaws within it that undermine the results it purports, yet it is cited widely and used to guide management. These flaws include the following: (i) the sample is not representative of the cohort they set

out to assess and priori power calculations are not adhered to; (ii) the study does not make clear how it standardised intervention delivery; (iii) reporting bias and therapist bias are not adequately dealt with; (iv) results are unclear, statistical relevance is reported, but not substantiated as being clinically significant; (v) measures are not clearly explained, the researchers used an invalidated patient diary to collect data and rationale behind the time-frame used which is not explained; (vi) a clear explanation of their statistical analysis is not given.

A similar programme of psycho-education was instituted by the UK NHS National Refractory Angina Centre, Liverpool, in the 1990s. In 2007, the team at the centre (Moore et al., 2007) published the results of this well-established programme, allied very closely in its design to the Angina Plan of the Lewin et al. (2002) paper. The authors identified specific misconceptions and angina threat avoidance behaviour, as part of their assessment and dealt with these, specifically, during clinical input. They report that such intervention significantly decreased hospital admission rates which, in turn, suggests that patients had become better at self-management of their condition. However, this research is, again, seriously flawed in its lack of the use of a control group.

This lack of robust design is not uncommon. Rees et al. (2004) undertook a review of Randomised Controlled Trials (RCTs) of non-pharmacological psychological interventions within CR, to determine the effectiveness of such interventions, on behalf of the Cochrane Review. Thirty-six trials, with 12,841 patients were included. The reviewers concluded that the quality of many of the trials was poor, with the majority not reporting adequate concealment of allocation, considerable heterogeneity observed between trials, evidence of significant publication bias and only six blinded outcome assessors. Combining the results of all the trials showed no strong evidence of effect on total cardiac mortality, or revascularisation. However, there was evidence to suggest that psychological intervention caused small reductions in anxiety and depression, in patients with CHD. Other reviews and meta-analyses (McGillion et al., 2008) have concluded that

the effectiveness of such interventions remains inconclusive. This is due to methodological problems, with respect to sampling, randomisation, controls and measurement.

3.2.2 Experiencing stable angina pectoris

A small number of studies have sought to explore the experiences of SAP sufferers (Miklaucich, 1998; Dixon et al., 2001; Plach et al., 2001; McCallum and Lindsay, 2001; MacDermott, 2002; Furze et al., 2005, Ononeze, 2006). These studies demonstrate some cross-over of themes related to the sufferer keeping going, while regaining control, accepting limitations imposed by SAP and making “*necessary*” adjustments to lifestyle.

In her phenomenological study of seven chronic angina sufferers (symptoms > 2 years) MacDermott (2002), outlined several themes which demonstrated a process of reluctant acceptance. These ranged from surprise at developing SAP to resignation about having to live with CHD; adjustment to the limitations caused by SAP, but with ongoing trepidation about future prosperity. This study outlines the tension that SAP creates in a person's lifeworld, and highlights the everydayness of this condition.

Although insightful, the author does not give us any information about the ages of participants, their gender, or socio-cultural background. The type of phenomenological approach adopted is also not outlined. Unfortunately, in her conclusion, MacDermott (2002) falls back upon a recommendation for ‘The Angina Plan’, without regard for its failings (already discussed). Rather she could have attempted to say what her study might add to this cognitive-behavioural care approach.

In an earlier and yet more detailed phenomenological / grounded theory study, Miklaucich (1998) undertook to understand the lived experiences of eight women (50-70 yrs.) with SAP. As with MacDermott's (2002) paper, her findings were of their time and may not necessarily be relevant to current treatment practices, and consequently patient experiences; however, they are still worth highlighting. Miklaucich

(1998) identified six main themes from six months of repeated interviews. These were similar to the study by MacDermott (2002) related to accommodation to limitations caused by SAP, however the author also more fully explored spatial and temporal themes. These included: (i) *Living between fear and safety* – this was related to feelings places evoked, e.g. hospital versus home, the latter viewed as a safe and familiar environment free of impositions; yet, at the same time, having concerns about distance to the hospital and how quickly it could be accessed, if they had a cardiac emergency, and, (ii) *Accepting limitations on life* – the author identified three stages in this temporal theme of progressive acceptance of angina. The first is “*allowing angina as little impact on life as possible*”; the second “*living life based on being ill*”; the final stage, “*waiting to see what would evolve*” (Miklaucich, 1998, 1214).

Miklaucich (1998) successfully creates a sense of journey, in the way she represents the temporal nature of the lived experiences of angina. The movement from one state to another is apparent in her study and makes it more multi-dimensional than MacDermott’s (2002) paper. However, I was left somewhat confused by her use of both phenomenology and grounded theory, as the two appear methodologically incongruent.

Both studies are heavily descriptive, rather than interpretive and neither study discusses the impact of social-cultural influences or support. Yet, it has been demonstrated that social support is an important predictor of emotional states, quality of life and perceived control, in people with CHD (Bennet et al., 2001). It has also been evidenced how cardiac patients with adequate family support are likely to experience fewer depressive symptoms and feel more in control over their illness (Rueda and Perez-Garcia, 2006).

Ononeze et al. (2006, 594) evidenced the experiences of eleven angina sufferers as part of a larger study which considered patient and healthcare professionals views of sociocultural influences on cardiac behaviour. Here the authors concluded that patient’s experiences and secondary cardiac behaviour were influenced by “*previous ideas about*

heart disease, based on the experiences of other people and from information in the public domain". Although the authors do not differentiate between those with SAP and MI, this inference that socio-cultural factors may influence SAP experiences raised an important point relevant to my own study and review of the literature. Not only did I need to consider the influence of partners of those with SAP, but also the literature pertaining to SAP in a farming culture.

3.2.3 Partners experiencing heart disease

A number of studies have considered the experiences of partners of those suffering cardiac illness, in an attempt to better understand the importance of such relations, in its management, as well as impact upon the partner; examples include: coronary heart disease (Lidell, 2002; Karner et al., 2004); heart failure (Agren et al., 2009; Rohrbaugh et al., 2009); myocardial infarction (Bennett and Connell, 1998; Svedlund and Danielson, 2004; Eriksson et al., 2009); cardiac arrest (Bremer et al., 2009); and after coronary artery bypass (Robley et al., 2010; Macleod, 2011; Whitsitt, 2009).

A number of these studies describe how experiences are temporal and transitional, usually starting with a dislocation of their lifeworld, through the introduction of illness, struggling to come to terms with it and finding new stability.

According to Ussher and Sandoval (2008) women carers often adopted a position of over-responsibility and self-sacrifice, remaining silent about the physical and emotional rigours of the carer role. Arenhall et al. (2010) reviewed the experiences of twenty women, following their partners' return home after a myocardial infarction. The authors highlight three experiential themes: (i) *Limited life space* – a number of the women felt stifled by the change of role necessitated, in their view, by their partner's illness. They felt obliged to take on more everyday responsibilities and physical workloads, to counter the need for their partner to pace themselves. This meant they had less free time to pursue other interests and, in turn, their lives felt suddenly more limited.

(ii) *Sense of life lost* – the women felt that companionship with their spouse had been lessened, since his heart attack. There was a less intimacy, or desire to undertake social engagements, where they could interact with others, as a couple. The women expressed this as a feeling of loss in their relationship; they missed doing activities together, and lamented that they missed their former partner, before illness. (iii) *Another dimension of life* – their partner's diagnosis brought with it uncertainty for the women about future wellbeing and how they would live with heart disease. Some described wanting to escape their relationship, due to the pressure this change put upon them. Others felt the crisis had reaffirmed the strength of their relationship and that they now strived to share life and be more open with each other. It also led to a better understanding of themselves.

Limitations on life, detachment from their partners and sense of loss, as well as loneliness were themes echoed in Eriksson and Svedlunds's (2006, 321) study, in which the women voiced that they wanted to be "*loved as a wife and not as a care provider*" by their partner, despite his chronic illness and their "carer" role. More positively, however, Macleod (2011) found that female caregivers of men recovering from CABG were able to reflect that they had been through a process of transformation, which gave them a new understanding of themselves and increased personal awareness, as well as motivation to "*live life*".

3.2.4 Couples dealing with heart disease

How couples manage heart disease has been looked at from a number of perspectives. These include patient and spouse perceptions regarding heart disease (Karner et al, 2004; Benyamini et al., 2007); how it effects relationships (Mahrer-Imhof et al., 2007; Dalteg et al., 2011); how dyads make lifestyle changes when faced with such a condition (Sher and Baucom, 2001; Goldsmith et al., 2006). Little, however, has been published regarding how couples manage SAP, specifically, or in the context of a farming background.

Walker and Luszcz (2009, 475), in their systematic review of health and relationship dynamics in late-life couples, argue that,

“The knowledge that spouses can have a significant impact on each other’s wellbeing needs to be recognised as to legitimate elements of an individual’s social context, and hence represents an important contribution to health”.

Dyadic coping with illness is influenced by broad socio-cultural factors, such as gender roles, as well as more proximal contextual factors, such as positive and negative marital relations (Berg and Upchurch, 2007). Berg and Upchurch (2007, 920) also highlight the temporal aspect of dyadic coping, stating that,

“Dyadic coping may be different at various phases of life span, changing temporally at different stages of dealing with the illness as well as unfolding daily as spouses interact around dyadic stressors”.

Mahrer-Imhof et al. (2007) looked to investigate the impact of cardiac disease on a couple’s relationship. They interviewed 24 couples and found that dyads demonstrated three distinct patterns for dealing with illness: (i) in some couples illness is a transforming experience that brings them closer together through their joint coping; (ii) other couples experience illness as a threat which imposes fear on each partner, where challenges are faced as mutual tasks; (iii) finally a number of couples see the development of disease as a missed opportunity to change their lives; these couples are disenchanted, but slowly return to a level of normality, albeit with more distanced relations.

Dalteg et al. (2011) undertook a systematic review of ten years of literature, up to 2009, their aim being to identify how the partner relationship is affected by cardiac disease. They identified five relationship themes related to myocardial infarction, arrhythmia and / or heart failure where the male is the patient and female his carer:

- *Overprotection* – patients reported feeling overprotected by their spouses, particularly regarding physical activity and lifestyle changes. This led to arguments and conflict, due to the growing

frustration and resentment that this imposed control caused patients. Partners, on the other hand, reported feeling constantly worried when the patient performed exerting activities, or went out alone, due to a fear that they might suffer another cardiac event.

- *Communication deficiency* – dyads experienced communication difficulties concerning the emotional impact of cardiac disease. Partners found it stressful dealing with the patient, during their recovery, and withheld their own feelings, so as not to disturb them further. However, it was found that those partners who actively disengaged their feelings, completely, only caused further anxiety in the patient. Being unable to talk through the experience or possibility of death also silenced many couples, unable to find the words or strength to confront such issues.
- *Sexual concerns* – the review found that most couples experienced issues related to their sex life, following the onset of cardiac disease. This was due to a number of reasons, including sexual dysfunction, up to six months post a heart event and also due to medication, as well as fear of resuming sexual activity, due to risk of further cardiac injury.
- *Changes in domestic role* – following a cardiac event, most couples experienced a transient shift in their relationship roles and responsibilities, where the spouse had to take on additional tasks to help or take over from the patient. Dealing with household tasks which had previously been shared caused some frustration and anxiety (Dalteg et al., 2011, 146).
- *Adjustment to illness* – following the onset of illness, a number of lifestyle changes took place for couples. These included new health practices, such as improving diet, or decreased joint activities and physical activity, as couples tried to live more calmly. These changes caused resentment in some couples but, in others, it triggered feelings of solidarity. Couples longed for a return to normality and rebalance in their relationships. Even though most couples experienced great distress, many reported that the illness had ultimately brought them closer together. However, some

couples did withdraw further from each other, linked to poor communication between them and ongoing spousal anxiety.

Benyamini et al. (2007) undertook an investigation of the perceptions of patients and their spouses towards heart disease. The authors found that there was a link between illness perceptions and quality of spousal support. Firstly, the way in which a person perceives the threat of a health issue influences how they react to it and cope, over time. This is also undertaken, in a social context, e.g. the reactions of family members can also affect their interpretation of illness and coping ability. Patient perceptions of their health problem can also affect *“their expectations regarding spousal support and therefore their appraisal of such support”* (Benyamini et al., 2007, 766). Secondly, partners of ill patients also engage in the same processes of self-regulation, where their own perceptions of their spouse’s illness influence their coping ability, support to the ill person, as well as how they view effective support. Thirdly, discrepancies between how each member of the dyad perceives illness might affect the well-being of both parties. The authors highlight from previous studies how partners engage *“in activities of surveillance and over protectiveness of the patient, possibly as an expression of guilt or manifestation of their need to manage their own anxiety”* (Benyamini et al., 2007, 768).

Benyamini et al. (2007, 781) argue their findings *“underscore the importance of attending to both partners’ perceptions when planning interventions aimed at improving recovery from, and adjustment to, illness”*.

3.2.5 Review of SAP section

Although SAP was first recognised in the 18th Century, controversy regarding its medical treatment (NICE, 2011) or our understanding of its experiencing or management from a psychological / sociocultural or lifeworld perspective remains small. Research indicates that SAP has a marked effect upon QOL for the sufferer (Gravely-White et al., 2007)

and yet it is difficult to accurately evidence why; other than the limitation it places on lifestyle (MacDermott, 2002), some sufferers fearing death, and subsequent adoption of fear avoidance behaviours (Furze et al., 2005). It appears that the introduction of heart disease in dyads effects the partner detrimentally, as well as the sufferer (Lidell, 2002; Karner et al., 2004). This also includes experiencing limitations on life, detachment from their partners and sense of loss, as well as loneliness. The way in which partners perceive their spouses illness effects their own coping strategies towards it and ongoing relations with their them (Benyamini et al., 2007). The way couples deal with heart disease also appears to have an effect upon each person's wellbeing (Walker and Luszcz, 2009). Finally, dyadic coping with illness appears to be influenced by broad socio-cultural factors, such as gender roles, as well as more proximal contextual factors, such as positive and negative marital relations (Berg and Upchurch, 2007). From this review it would appear important to consider both the individual SAP sufferer, their partner, dyadic coping strategies along with the prevailing socio-cultural backgrounds of dyads when planning a SAP rehabilitative programme. I will now review health, illness and more specifically heart disease from the socio-cultural context of farming, as this is the particular group of people I planned to investigate.

3.3 Part Two: Farming and Health

Farmers from industrialised countries have been shown to have poorer physical and mental health than the general population. Several reasons are suggested for this: ageing, economic difficulties, risk of injuries, work-related illness, and exposure to pesticides (Saarni et al., 2008). Syson-Nibbs et al. (2006), for example, undertook a population survey of the health needs and services' utilisation of the farming community, in Tideswell, located in the heart of the Peak District National Park; 496 people within a GP Practice were assessed, 248 people from the farming community. Significant differences were found between the two groups; farmers were identified as having health

needs that were greater than those found in the local non-farming sample, particularly related to arthritis and depression.

Moreover, there is also growing acknowledgment of the psychological hazards of farming, including high stress, linked to a high incidence of suicide (Fraser et al., 2005). That said, it appears suicide rates have dropped, partly through specific targeting of the industry, due to its previous poor record (Roberts et al., 2013). Despite the recognition that agriculture is one of the most dangerous occupations, with a higher than average incidence of chronic musculoskeletal conditions and mental health issues, the profession remains medically under-served, due to geographic and attitudinal restraints (Anderson et al. (2012).

3.3.1 Farming and heart disease

A number of studies have sought to consider whether those employed in agriculture have a higher risk of heart disease, than the non-farming population. An increased risk of ischaemic heart disease (IHD) has been linked to the inhalation of organic dust particles, mites and moulds, particularly in swine farmers (Sjogren et al., 2003). Chikani et al. (2005) in their study of 1500 U.S. farm and non-farm female residents, found that the former had a higher prevalence of cardiovascular risk factors linked to psychological job stress. More recently, Brumby et al. (2012) found that Australian farmers and farm women had a higher incidence of CVD risk factors, related to obesity, diabetes risk, hypertension and psychological distress, as well as high alcohol consumption. However, other studies have concluded that there is no significant difference in cardiovascular risk factors between farmers and non-farmers (Prokosch et al., 2011). Indeed, it is argued that farmers may have a significantly lower morbidity and mortality rates, due to CVD, than their urban counterparts (Stiernstrom et al., 2001).

However, the pressure such illness places upon farmers, while trying to uphold their livelihoods, has been recognised. As long as fifty years ago, Gripe et al. (1961, 364) stated that:

“The nature of the farm business makes the impairment of the farmer in the acute stages of heart disease a serious threat not only to the man but also to the future of the business ... Apart from his medical skills, the physician's success will depend upon some understanding of the stresses of farm work and means for their reduction. The instructions to the farmer in the area of work must be specific. Compliance will often be better if the family is well informed. Acceptance by the community of the fact that most farmers with cardiac disease are able to work within limits is essential to satisfactory rehabilitation.”

More recently, King et al. (2006) reviewed how gender and ethno-cultural factors influence health behaviour changes, after a diagnosis of CVD. They found that farmers *“carried a heavy concern and financial burden when they were ill or recovering from a cardiac event”* (King et al., 2006, 1098), where participants also found it difficult to balance the need to recuperate against the daily demands of the farm. Crucially, there was a financial consequence to heart disease, due to loss of labour, time and productivity, as well as rehabilitation costs. The distance to health services and the time it took farmers away from the farm were all barriers to engagement in such programmes. King et al. (2006, 1100) concluded that rural men and women (particularly from a farming background):

“gauged their health based on the work in which they could engage”, arguing that only *“when healthcare providers understand and work with the gender and ethno-culturally based components that influence people’s appraisal of their cardiac health and their decision-making, appropriate secondary prevention interventions and positive health outcomes are more likely to follow”* (King et al., 2006, 1091).

3.3.2 Farm stress

In 2005, the HSE published ‘Farmers, Farm Workers and Work-Related Stress’ (Parry et al., 2005), a qualitative study exploring the ways in which stress affects farming communities in the UK, how it has changed

in recent years and the degree to which work-related stress can be helped by support interventions.

The authors attempted to distinguish between intrinsic, extrinsic and work-related dimensions of stress, in their interviews of sixty key informants and members of five farming communities, across England and Wales. They found that many of the intrinsic aspects of stress were part of the respondents' traditional expectations of the challenges inherent in farming. These included: seasonality, adverse weather, stock crises and disease. Extrinsic dimensions of stress were mostly suffered by the principal farmer and included: the current legislative and political framework, the media and public perceptions of farming, competitive forces and prices for produce. Finally, the work-related aspects of stress in farming emerged in a range of roles. They included: potentially dangerous farm practices, workload (particularly seasonal variances), rising paperwork, and tension linked to family farms and acquisitions.

Coping strategies and support were discussed with interviewees. Having time for relaxation, the pursuit of leisure activities and seeing friends, socially, provided an important counter to the stressors of work. There was a preference for locally available sources of formal support, e.g. local agricultural groups, trusted vets and doctors. The study also found that there was a strong emphasis placed on having a supportive family. The farmers' wives had the important role of emotional caretaking. However, this could place extra strain on farm women. Stock crises and increasing paperwork also affected farm women, more so than the principal farmer, endured alongside the emotional stress of worrying about their families' welfare. By contrast, family farm workers and labourers tended to lack the autonomy of land-owning farmers, with work-related stress concerning work-load and organisation making up a greater part of their stressors.

Although the report discusses the physical effects of stress, it does not go into details regarding the effect that physical problems and illness has on stress. Cardiovascular disease is not considered within the report. Lack of sleep, physical exhaustion and back problems were the

most commonly reported physical health problems related to farming. Despite this, few interviewees reported taking much, if any, sick leave, over the past year. Indeed, a common pattern was to work through illness, and a feeling of being unable to justify taking time off, unless they were bed-ridden, particularly in those who worked on small farms. The study also found that most interviewees were usually able to find a way of working around their health issues, so that others on the farm, or their stock, did not suffer.

Significantly, several studies have highlighted that the stress farmers uniquely report is not linked to health, specifically, but rather to paperwork, regulation, insularity, image, family relations and over-work, which are all flashpoints in farmers' work-related stress (Parry et al., 2005). In this context, Price and Evans (2009) are critical of the established and medicalised view of farm-related and rural stress. They argue that a more conceptualised view is required, to understand the complex causes and origins of farming distress. *"Medical outcomes can be interpreted more fully if linked back to the pressures emanating from a way of life that is historically and culturally patrilineal"* (Price and Evans, 2009, 9). The authors present a framework highlighting four conceptual, interrelated clusters which they state help to re-contextualise and de-medicalise farming distress. This echoes the findings by King et al. (2006), to which I referred earlier, who consider gender and ethno-cultural considerations vital in understanding and thereby structuring effective healthcare to attend to the unique needs of rural, and more importantly, the farming community.

3.3.3 Framework for understand farming distress

Price and Evans (2009) argue that their proposed framework helps us to understand, in its entirety, an individual's farming life; this can then act as a platform from which the *"subjective realities of distressing events"* can be properly illuminated. Theirs is an original intent to present a lifeworld view of the farmer's existence and introduce us to the depth and inter-relatedness of its elements. I present their model to

the reader because I make reference to it at various times from this point forwards, particularly during my discussion section. The authors highlight four domains which naturally follow and build upon each other, starting with “*farming identities*”, set against the prevailing macro-economic context (see diagram A).



Figure A: The framework of farming families’ clusters of non-medical distress (adapted from Price and Evan, 2009).

3.3.3.1 Macro-economic context

In the same way that a hermeneutic phenomenological view requires some grasp of background context to help interpretation (Addison, 1989), so, too, insist Price and Evans (2009) does farming, to help frame the conceptual clusters within prevailing socio-cultural influences. UK farm incomes have been in long-term decline, since the 1960s, reaching a low point, in 2000. The contribution of agriculture to the economy has also dropped considerably, since the 1960s, with a similar

trend in the farming workforce (<http://www.ukagriculture.com/farming>, accessed 16/02/14). Following the Second World War, until the early 1970s, political emphasis was placed on farmers to secure the country's food supplies and this progressed under a "*productivist*" model, maximising food production (Burton, 2004). This approach was supported by production-oriented subsidies, in which farmers were financially rewarded for their endeavours: "*the production-oriented roles came to symbolise, both to farmers and to the country, the notion of good farming practice and enabled farmers to claim a high social position as caretakers of the nation's food supply*" (Burton, 2004, 195). However, a change to the way farming is viewed, over the last forty years, has forced successive governments to rethink their attitude towards agriculture, in the UK. According to Burton (2004), three successive phases have created this shift, namely:

- the rise of environmentalism, in the late 1970s;
- problems related to over-supply and financial issues, in the 1980s;
- and
- the emergence of health issues in the 1990s and 2000s, linked to BSE, foot-and-mouth disease, to name but two.

The result has been a restructuring to the subsidy system and a move towards voluntary schemes aimed at steering farmers away from their reliance on traditional productivist methods of farming, towards more diversified enterprises, e.g. shops, leisure providers, foresters, conservationists, etc. (Burton, 2004).

Burton (2004) argues that schemes to help farmers make these transitions have met with only limited success, suggesting that the reasons for this have been commonly linked to low financial returns, against large set-up costs, or perceived lack of skills to pursue such changes. However, Burton (2004, 196) argues that farmers might also resist change, due to "*an anticipated loss of identity or social / cultural rewards traditionally conferred through existing commercial agricultural behaviour*". This challenge to the "*good farmer*" image, he argues, is beginning to emerge out of studies which seek to understand farmers'

responses to government schemes. Price and Evans (2009), in their review of distress, in Powys farming families, found that a perceived lack of political and economic support left farmers feeling marginalised, undervalued and misunderstood. They also highlighted that, when opportunities to diversify were offered, these were *“juxtaposed against a responsibility to the past ... generational traditions founded in different sets of political and economic circumstances”* (Price and Evans, 2009, 5).

3.3.3.2 Farming identities

Price and Evans (2009, 6) contend that individuals are socialised into gendered farming identities, in many cases, from birth. They *“come to know the expectations on them from all viewpoints of time; past, present and future. Hence, individuals come to know their sense of belonging to a place and the gender identity of who does what, where and when in that place”*. These gendered identities are rooted in the farm and its culture, to such an extent that the male farmer can perceive of no other role, in many cases. Farming women, who follow a similar upbringing, support the male's position through their own enactment as the farmer's wife. From this perspective, it is understandable why anything which threatens these personal identities, (e.g. lack of profitability, ill health, retirement), might create a distress that is untenable. In such cases, the authors argue, suicide might appear to be a viable option, *“so keenly is their sense of personal identity linked to the places and spaces of farming”* that they are unable to contemplate another existence (Price and Evans, 2009, 7).

Eric Ramirez-Ferrero, in his influential book titled 'Troubled Fields' (Ramirez-Ferrero, 2005), highlights the pressures that agricultural modernisation and restructuring have had upon farmers. He argues that,

“Global dynamics of change, including market transitions, urbanization, migration, cultural patterns of exclusion, marginalisation, and poverty,

are all internalised by subjects. They are personally experienced by those most vulnerable to its effects – those least capable of shielding themselves from the realities of cultural change” (Ramirez-Ferrero 2005, 174).

Ramirez-Ferrero states that cultural farming pride is no longer compatible with “*progressive*” agriculture and this, in turn, has made male farmers feel devalued and question their place, or even existence.

3.3.3.3 Farming relations

Following on from these notions of prevailing gendered identities, Price and Evans (2009, 7) next consider how farming relations impact upon distress. The authors argue that so entrenched and deep rooted are these gendered identities, that they often leave the imbued powerless to change: “*Maintaining a public version of male and female relational farming gender identity and conforming to farming stereotypes, so bound up in emotions, disarms individuals of choices*”. Furthermore, they suggest that when subjectivities of what it means to be a farming male and female within gendered farming relations are challenged, then feelings of distress can emerge.

Spouses who are introduced to farming sometimes find it hard to understand and reconcile the customs of this way of life, which can lead to relational tensions (Danes and Lee, 2004). On this subject, Price and Evans (2006) also suggest that there has been a subtle change in the way farming relations are viewed. The authors state that farming families still plan for generational survival, on the farm. This sometimes encourages the family to seek women who are able to bring a dowry with them, and to be “*good as gold*” in not exercising their full legal rights, once established within the family. However, the authors found through interviews with farmers, in Wales, that young women are increasingly looked upon warily, as potential “*gold diggers*”, not interested in making the sacrifices necessary to maintain the future of the family farm business, above their own monetary self-interests. This

new perception was a major source of fear for the future, in both farming men and women (Price and Evans, 2006, 287). Clearly, young women choosing divorce over staying in an unhappy relationship is reflective of divorce patterns, more widely. However, the survival of the farming family's way of life can also be placed in jeopardy by such events, "*actively weakening firmly established modes of succession and inheritance as a result*" (Price and Evans, 2006, 292).

3.3.3.4 Farming gender roles

As Price and Evans (2009, 7) state: "... *maintaining gender roles, essential for family survival in farming has become an increasing strain*". They argue that changes in the macro-economic climate, as well as wider societal values mean that such roles are more difficult to adhere to; the roles of both men and women are having to diversify, to maintain profitability for the farm. Such diversity, however, can lead to increased burden, anxiety and distress. Women, often labelled "*the invisible farmer*", are seen as an extra pair of hands on the farm at busy times of the year, but without control or pay. This is in tandem with a multitude of other duties, e.g. home domestics, mother and other care-giving duties; in some cases, undertaking part-time work away from the farm. This pluriactivity of roles can bring with it the distress of overload, when the individual is unable to meet demands.

Shortfall (2002) also believes that the gendered nature of farming roles is slowly changing, due to agricultural and rural restructuring. She argues that the increasing amount of off-farm work and involvement in rural development policies, in which women are engaged, has given them greater financial independence and negotiating influence related to the family business. However, she does not see this as overturning the substantial weight of culturally-born and patrilineal-led gender roles which still exist in UK farming. Shortfall (2002) argues that it is the practice of off-farm working that helps to maintain the farm's viability and keeps it a predominantly male domain. Although the absence of wives from the farm can also have a detrimental effect upon the male

farmer's wellbeing, potentially feeling less supported and more isolated in his work. Shortfall (2002) also suggests that some male farmers find this change in economic relations with their partners difficult, due to a sense of failure as the primary breadwinner.

Melberg (2003) argues that the pluriactivity is not just seen in the role of females; increasingly, men are having to consider off-farm work, to help maintain an income. According to the author, the pluriactivity of both partners can add to the cumulative stress, decreased wellbeing and relational conflict of farming dyads. Price and Evans (2009) also suggest that the gendered expectations of certain work roles mean that an individual might feel he / she must fulfil that role, even when they feel unsuited towards it.

3.3.3.5 Home symbolism

Price and Evans (2009, 8) argue that there is an ideological pressure for many farmers to maintain their name on the land. For some, this might manacle them to a work and lifestyle which they do not wish to follow; *"anxiety stems from this paradox"*. The mechanisation of farming has led to a sizeable decrease in the number of workers required on farms, which has led some farmers to feel more isolated. Simultaneously, according to Price and Evans, 2009, 8) this has not encouraged the farmer to take up a more active role in the home, where a segregation of *"domestic"* duties to the farmer's wife remains: *"family farming may see men in the home, but not of the home"*.

The interface between home and work life can have an impact on health, when demands in either increase and / or interfere with the other. The potential for this to occur is heightened, when an individual owns or is part of a family business (McShane, 2011). A family farming business represents a merging of work and home environments and *"is typified by blurred boundaries and dual roles. Additionally, work demands are often erratic as they are dependent on factors which may be beyond individual control (e.g. soil quality, weather conditions) and therefore supersede family needs"* (McShane, 2011, 46). McShane and Quirk (2009) argue that farmers should not be seen in the same

light as other home-based workers, as much of their work is actually outside of their home. However, their often high work demand, particularly the 24-hr. nature of farming life, can lead to degradation between home-work boundaries.

Riley (2009, 666) is critical of what he perceives to be “*the gendered division of productive (farm) and reproductive (home) spaces, wherein a woman’s place is in the home and a man’s place is toiling the land*”. He adds that gender is not fixed, but is remade constantly in response to need and that the role of men and women is “*more complex, nuanced and temporally contingent than is often presumed*” (Riley, 2009, 667). In his review of farming families, in the Peak District, Riley found that women often undertook farming roles, and took charge of tasks often posited as “*male*” pursuits. It appeared from his study that, although there was a pervading patrilineal underpinning to families, roles were nevertheless fluid, the prosperity of the farm seen as more important than individual identities. “*Togetherness and teamwork*” marked out such arrangements, rather than subordination. He also found that, on the majority of farms, it was the women who took charge of the paperwork associated with the business. He argues from “*within ostensibly patriarchal structures women have been able to forge new positions and identities ... gathering prestige and being seen as equal partners*” (Riley, 2009, 678). He concludes that women are now important in farm decision-making, directing the practices of farms, in many cases. They are not merely passive actors, but active agents in the business, a temporal process of change in gender roles and “*women’s creative adaptation to the new situations which are part of the progression of the family farm*” (Riley, 2009, 269).

It appears unclear from the literature whether farming individuals are more at risk of developing heart disease than their non-farming neighbours, particularly SAP. However the socio-cultural factors related to an agricultural lifestyle may impact negatively upon their accommodation to such illness. Certainly when approaching ill health within this group, considerations of non-medical causes of distress

(according to Price and Evans, 2009) also need to be undertaken, as these might be integral to the persons suffering and ability to successfully manage of illness.

3.4 Summary of the Chapter

A literature review of representative research appertaining to the Farm Angina Project is presented, in this chapter. As such, this chapter was divided into two sections. The first section comprised a review of SAP from a medical and experiential perspective. It also featured how couples cope with heart disease. In the second section, I gave an overview of health, from a farming perspective, and explored how clusters of non-medical distress can affect and be impacted by illness. Based on a review of the literature, the limitations of SAP, set against the rigid farming lifestyle, may be a toxic combination for a farming individual. It is not unreasonable to suggest that, based on the evidence of other studies, the physical consequences of SAP will have an impact on the farmers' abilities to undertake their role; it is not then unreasonable to expect that this will increase anxiety about job security, financial implications, and have a strain on family relationships. Maintaining gendered identities and roles within the changing world of agriculture appears to place men and women under strain. When these are challenged, for example by illness, then feelings of distress may emerge and add to suffering. This could have a disastrous effect upon the individual farmer, as well as his / her family if unable to farm. As Price and Evans (2009) discuss, individuals may consider suicide when a farming way of life is made untenable. Conversely, it may be that SAP impacts less on a farmer's quality of life than it does on the general population. Possessing a hegemonic 'masculine' outlook and a perceived need to prioritise their work over their personal health may offer a certain buffer from developing disabling misconceptions about their angina (Furze et al, 2005). However, it is not clear from the literature what effect SAP has on this particular group of people.

The literature review appears to highlight a gap in current understanding. A journeyed understanding of SAP sufferers' experiences against a backdrop of modern healthcare is needed; one that also considers close partners. An account that considers SAP sufferers and their partners from a farming background is also required, to better serve these groups within our community. Thus, the need to undertake a research project presented itself that aimed to seek to understand the experiences of farming dyads with SAP.

In the next chapter I will outline the research paradigm and philosophy underpinning my decision to undertake a longitudinal, hermeneutic phenomenological study, in order to uncover the research participants' lived experiences.

Chapter Four: THE RESEARCH PARADIGM AND PHILOSOPHY

“he is not himself
ill-tempered silence rules
our angina home”



“...he was certainly shorter tempered than I had ever known him, never known him to have a temper...umm and it was certainly effecting him, in fact I remember remarking to my sister, because I was quite worried that he might actually lose the plot with somebody in the village...”

Carol

4. Chapter Four: THE RESEARCH PARADIGM AND PHILOSOPHY

*“To understand the rose
One person may use geometry
And another the butterfly”*
Caudel (1929)

This chapter aims to provide details of the research paradigm and philosophy underpinning this study, before outlining the methodology that guided my choice and application of research methods.

4.1 Introduction

The Farm Angina Project utilised qualitative research, seated within an interpretivist framework, employing a discursive, qualitative approach, namely hermeneutic phenomenology, which was also longitudinal in design. It was formulated in this way to answer the question *“How do farming dyads experience SAP?”* This chapter describes the interpretivist research paradigm to which this study is allied; and sets out the epistemological and ontological reasoning upon which this thesis is built. It outlines the relationship between the research question and methodology chosen to investigate the experiences of the participants; it also aims to establish a foundation upon which continuity in method, analysis, as well as quality can be observed and assessed.

4.2 Qualitative Research

Qualitative research techniques are now commonly used within the social sciences; however, within a clinical setting (with a heavily positivist and therefore quantitative research bias), they are still regarded with some suspicion as to their validity and scientific worth: *“coming from different epistemological and ontological traditions,*

qualitative enquiry does not fit the conventional idea of 'research' or 'applied science'" (Macdonald and Carnevale, 2008, 2). Certainly this fit with my experience of research within healthcare. During the planning of this study the Cardiology Department employed a nurse to co-ordinate its research activity. None of her portfolio were qualitative and when questioned she admitted that there weren't any such trials currently available. The disciplines peer-reviewed research publications, such as the 'Heart Journal' also carry a heavily quantitative research content. Anecdotally, whilst discussing the Farm Angina Project with a Cardiologist he even ended our discussion by asking me "*what did the numbers show?*" I was taken by surprise by this and his apparent inability to grasp what my qualitative approach actually meant. However this encounter underlined the strong positivist mind-set towards patient research in my opinion. Regardless, Macdonald and Carnevale (2008, 2) state that qualitative research offers conceptually rich analysis from which healthcare research can benefit. The authors argue that this can help inform policy and practice within healthcare settings and foster advancements, because it helps to stimulate discussion, and more individualistic conceptualisations. I therefore considered this the right approach for my study.

4.3 Ontology, Epistemology and Axiology

It is argued that method-bound qualitative research is unsound research, as it ignores the philosophical, ontological and epistemological framework in which procedures should be based (Carter and Little, 2007; Koch, 1995). Hence, there is a need to carefully and cyclically relate method to methodology, methodology to ontological and epistemological positions. In this way, qualitative research maintains its rigour.

Ontology and epistemology are easily confused (Carter and Little, 2007) and so it is necessary to clarify each and distinguish where this research sits within both domains. Ontology is the science or theory of

being – or “what is” and asks “*what is out there to know?*” There are two broad, conceptualising perspectives available when considering these questions. Positivist frameworks view reality as an objective “out there” separate from ourselves. On the other hand an interpretivist framework supports the belief that reality is constructed and can be modified by the knower; in other words reality is not “out there” but rather is specifically formed by individuals (Laverty, 2003).

Epistemology is the theory of knowledge and asks “*what and how can we know about it?*” Marsh and Furlong (2002, 19) state that the researchers’ “*epistemological position reflects their view of what we can know about the world and how we can know it*” (Marsh and Furlong, 2002, 19). A number of positions are available to the researcher here between two juxtapositions. The first is a belief that knowledge can be objectively measured, in that everyone observes things in the same way. The second position posits that observation is never objective, but always affected by social constructions of reality. Positivists would take the former view, while post-positivists, constructivists and interpretivists take up the juxtaposing positions, to varying degrees. Qualitative methods are employed by these latter groups. As Marsh and Furlong (2002) state, the foundations upon which a researcher works are their ontological and epistemological positions.

Consideration of axiological issues is also a requirement of the research paradigm. In this respect, it is the values upon which ontology and epistemology rest and can be assessed. In hermeneutic phenomenology, this involves recording the “*researcher’s values and opinions in the process of knowledge generation*” (Kafle, 2011, 194) and recognising that the researcher is part of the process.

4.4 Interpretivist Paradigm

This study adopts an interpretivist paradigm which assumes that individuals understand and make sense of situations through their present experiences, relevant memories / past markers related to the

situation(s), as well as futural expectations. In this way meaning is fluid, temporal, and is continually reconstructed over time. As Flowers (2009, 3) suggests *"It is these multiple interpretations that create the social reality in which people act."*

Interpretivism is based on a more humanistic philosophy than positivism and provides a basis for a wide variety of qualitative research, such as grounded theory, phenomenology, ethnography, and hermeneutics. As Loftus (2006, 105) reflects, the interpretive paradigm recognises that meaning is a human construction and is dependent upon contextual features such as: *"the particular history, place, and culture that people bring to any act of meaning-making. Perfectly valid meanings can therefore vary from person to person and change within one person according to circumstances."*

4.5 Hermeneutic Phenomenology

This research follows an interpretative phenomenology doctrine, namely hermeneutic phenomenology, with a longitudinal approach. I considered this approach best suited the aims of the study and my own ontological and epistemological positioning within it, which I will detail through the rest of this chapter.

In regard to phenomenology, Langdrige (2007, 10) offers this definition: *"phenomenology (a compound of the Greek words phainomenon and logos) is the study of human experience and the way in which things are perceived as appear to consciousness"*. Phenomenology is usually located within the interpretive paradigm (Racher and Robinson, 2002); however, Annells (1999) argues that the multiple philosophical positions underpinning phenomenology make it transposable into most forms of research paradigm. Indeed, Husserl, acknowledged as the father of phenomenology, is often portrayed as a positivist and representative of that paradigm (Koch, 1995), although this has been questioned more recently (McDonnel-Henry et al., 2009). There are several unique perspectives of phenomenology; however,

two approaches are recognised as guiding the majority of qualitative investigations in health; these are descriptive and interpretative phenomenology (Wojnar and Swanson, 2007). Hermeneutic phenomenology originates from the work of Heidegger (1889-1976) and was developed by his student Hans-Georg Gadamer (1900-2002) among others. It sets out to describe humans as they show themselves in “*average everydayness*” (Guignon, 2012), in the same way as descriptive phenomenology, but instead acknowledges the “*explicit involvement of interpretation*” (Finlay, 2012, 110). In the relationship between researcher and participant, their inter-subjectivity is embraced, and interpretation offered as a means of uncovering the contextualised meanings of this relationship and research, as a whole.

Hermeneutic phenomenology runs counter to positivism as an approach to a study of humans, questioning the idea that we can truly gain objective facts about the properties of being human. From a hermeneutic perspective, “*the human is always meaning-laden, defined by the significances that it absorbs from its socio-historical context*” (Guignon, 2012, 99).

In the next section, I shall review the philosophical keystones of phenomenology, as related to this study, as a precursor to how they influenced decisions made regarding methodology and method.

4.6 Philosophical Foundations

This section describes the main philosophical tenets underpinning the hermeneutic phenomenological research study and relates these to my chosen methodology. Everything within this study is congruent with this approach, from my own ontological and epistemological position, through to my methodology, method and writing style. I was influenced primarily by the phenomenological philosophical writings of Heidegger, Merleau-Ponty and hermeneutics of Gadamer.

4.6.1 Phenomenology

Phenomenology is essentially the qualitative study of lived experience (Van Manen, 1997). Its emphasis is on the world as experienced by the person being researched, not the objective findings of scientific endeavour. As already discussed, phenomenology is actually an umbrella term which encompasses a range of philosophical views and research approaches. As a starting point, one can divide phenomenological philosophy and methodologies into two broad categories – descriptive (often called Husserlian) and interpretive (also known as Heideggerian or hermeneutic) (Finlay, 2011). Koch (1995) laments that these two approaches are often used interchangeably within research, without any regard to the fact they represent differing philosophical ideas. In her view, this serves only to weaken the quality of such research. Van Manen (2013) argues that professional practitioners tend to be less interested in the philosophy of phenomenological method than its practice and application. Indeed, it is claimed by some that phenomenology is a tradition only, with no common method (Zahari, 2013). However, as I have already highlighted, Carter and Little (2007) argue that such method-bound qualitative research is unsound. I recognise what Van Manen is suggesting, from my own experiences; it is tempting to concentrate on method when research practice is time-pressured, or the researcher is uncertain of their own positioning within it. However, I would contend that it is important to understand the differing philosophies of descriptive and interpretive phenomenology, so that one can reflect and maintain congruence throughout the research. I found such philosophical scrutiny acted as a guide, not an encumbrance. The philosophical keystones upon which I have built my research made me question my decisions at each point, and then offered me ways forward, not back.

At the core of The Farm Angina Project are the four lifeworld existentials (as described by Van Manen, 1990): corporeality (lived body); spatiality (lived space); temporality (lived time); and relationality

(lived relations with others). These were used to guide me towards an analytic depth I did not previously own, helping me to explicate meaning from participant narratives related to their lifeworld experiences. I will discuss these four existential, lifeworld dimensions in more detail later. The lifeworld is integral to all phenomenological approaches. The phenomenological lifeworld has its own history and would resemble an onion, if one could visualise it. Different philosophers have added their own unique perspective and layers, over that of their predecessors. How one views the lifeworld of participants in any research project is steered by the researcher's own beliefs about approach and layer of the onion he / she prefers.

The next section contains an outline of the significant historical keystones of the lifeworld from my perspective, to highlight what has informed my decision-making. How this relates to methodology will be dealt with, in the next chapter.

4.6.2 Husserl: Birth of the lifeworld

"Slowly the representatives that formerly symbolized families, groups, and order disappear from the stage they dominated during the epoche of the name. We witness the advent of the number. It comes along with democracy, the large city, administrations, cybernetics. It is a flexible and continuous mass, woven tight like fabric with neither rips nor darned patches, a multitude of quantified heroes who lose names and faces as they become the ciphered river of the streets, a mobile language of computations and rationalities that belong to no one" (Certeau, 1984, iv).

Edmund Husserl, the Austrian-German philosopher and mathematician (1859-1938), is seen as the founding father of modern phenomenology, who sought to create a new science away from the prevailing positivist view he considered responsible for a steady dehumanising of society (Finlay, 2011; McDonnell-Henry et al., 2009). In his seminal work, "The

Crisis of European Science and Transcendental Phenomenology: An Introduction to Phenomenological Philosophy” (Husserl, 1954/1970), the author argues that the Greek idea of a universal science which sought an all-encompassing truth had been trampled by a new wave of Cartesianism, driven by Galileo’s “*mathematization*” of nature, ultimately estranged from the realities of the “*lived*” world. Just like the quotation by Certeau (1984), Husserl feared the disappearance of man’s “*spirit*” to the “*number*”, and the globalisation of order; he was unable to accept this “*mathematically exact model as the guiding principle for the sciences of the ‘spirit’*” (De Vos, 2012, 325). Cartesian dualism, the splitting of the world into physical and psychical realms, allowed for the introduction of psychology; however, Husserl argues that psychology wrongly adopted the methodology of the mathematical or natural sciences in its attempts to “*solve the problem of subjectivity*” (De Vos, 2012, 328). For him “*dualism offers no place for subjectivity ... the psychical dimension is always under threat from a further encroachment of objectivism*” (De Vos, 2012, 328). In an attempt to parry this, Husserl sought to regain a position which allowed philosophers to look upon the “*subjective*” with a sensibility untarnished by reason; take a position of pre-scientific naivety. From his work, the phenomenological slogan “*to the thing themselves*” was first coined, expressing the desire to access the pre-reflective givenness of things in a way that would not be distorted by scientific theory and practice. This is in stark contrast with the popularist view of Husserl that suggests his approach was very much part of Cartesian dualism (McConnel-Henry et al., 2009).

As Galvin and Todres (2013, 25) state, Husserl wanted to maintain the qualitative ground that gave numbers (or words) their meaning, the “*textured, embodied, experienced world of coloured trees, sparkling stars, alternative ways home, remembered seasons, happiness, joy, anguish and sadness*”. In his attempt to do so, Husserl developed transcendental phenomenology, in which the lived world of everyday human experience, as it arises in consciousness, could be studied and

better understood; he described it as *“the study of the essence of conscious experience”* (Finlay, 2011, 44).

In his later work, Husserl introduced the notion of the lifeworld (*lebenswelt*), the immediately experienced world that we find ourselves in, consisting of invariant structures, such as (i) the *“body-subject”* which acknowledges that we all carry with us a sense of embodiment and sense of self, including our value-judgements, i.e. ethics; (ii) *“sociality”* where we relate to others in the world; (iii) *“spatiality”* how we perceive the world that surrounds us; (iv) *“temporality”* which states that we reside in an unfolding present, with a determined past and yet-to-be-determined future (Finlay, 2011, 45).

Husserl hoped this was the last piece in his creation of a new scientific viewpoint, transcendental phenomenology, offering a means *“to heal Europe of the objectification of all areas of life that the natural sciences were carrying out and to free humanity from oppression and prejudice”* (Pages, 2009, 73). From his revolutionary stance, the rest of the phenomenology movement has grown.

It appears through his writing that Husserl oscillated between two notions of his lifeworld. Originally, he perceived it as the foundation upon which everything else, including culture and historical context, is built. Over time, how a person lives is wrapped around this lifeworld, but does not influence its essential structure; this is the *“pre-given, silent world”* of the lifeworld (Dorfman, 2009, 296). However, how one may access this deeper essential lifeworld proved an issue for Husserl. He tried to resolve this problem through his introduction of the process of *“epoche”*, where one is able to suspend the elements of the lifeworld through *“reduction”*, a *“radical, self-meditative process where the philosopher puts aside the natural world and world of interpretation in order to see the phenomenon in essence”* (Finlay, 2011, 46). He articulated two steps required for attaining this state of openness and new way of seeing. The first reduction is the epoche of objective science – in which one brackets theory and knowledge and reduces the

field of investigation to the lifeworld, free of scientific facts. The second “*universal*” epoche of the natural attitude – in which one brackets the reality of the natural, taken-for-granted world, which then enables us to go beyond our own natural attitude and enter into a new realm, where we can now see experiences in their own natural attitude. Thus, the philosopher is freed from the pre-givenness of the world; the world becomes a phenomenon (De Vos, 2012, 330).

Smith et al. (2009) offer two caveats regarding the interpretation of Husserl’s work, from a practical perspective; firstly, that most of his ideas were conceptual and not related to the application of a psychological stance, per se; secondly, that Husserl was mostly concerned with first-person processes – self-analysis using a phenomenological lens – rather than a concern with other people’s experiences. Whilst Husserl was interested in capturing the essence of experience, Smith et al. (2009, 16) argue that most psychology researchers adopting a phenomenological viewpoint are concerned with the more modest intention of capturing particular experiences, as experienced by particular people. Husserl’s lifeworld was of the subjective, the inner world, looking out on the world of objects.

Husserl has been criticised by those, such as Carman, who argues that he never acknowledges the interpretative character of his enquiry, but instead puts up a smokescreen-pretence of scientific rigour, based on metaphysical prejudices (Carman, 2008, 55; cited in Martin, 2013, 111). Where Husserl’s apparent short-comings ended, his student Martin Heidegger continued to progress the art of phenomenological enquiry.

4.6.3 Heidegger: Being-in-the-world

Smith et al. (2009, 17) argue that just as Husserl was primarily concerned with individual psychological processes, e.g. perception, awareness and consciousness, Heidegger was more concerned with *“the ontological question of existence itself, and with the practical activities and relationships which we are caught up in, and through*

which the world appears to us and is made meaningful". Heidegger was interested in the concept of existence from a worldly perspective – embodied, inter-subjective and physically-grounded experiences.

As Husserl's assistant from 1920 to 1923, Heidegger shared similar fears as Husserl regarding the spiritual decline of humans, and what he termed the "nihilism" of the modern world; a world in which the "*question of being*" is forgotten and spiritual decline ensured by the pervading metaphysical view of itself. In an attempt to regain a perspective and acknowledgement of the subjective being, Heidegger turned to phenomenology. His aim was to give an account of our everyday being in the world, to "*describe how things initially show themselves immediately and directly in the course of our lived experience*" (Aho, 2009, 11).

Heideggerian phenomenology is based on the concept of the individual being as one with their culture, social setting, history, including the period of time they live (Wojnar and Swanson, 2007). In "*Being and Time*", Heidegger offers a "*radical critique of Western metaphysical thinking*" (Wollan, 2003, 31), introducing his account of what it is to be human, to exist and to recognise this existence. This sense of one's own existence he terms Dasein: "*This entity which each of us is himself and which includes inquiring as one of the possibilities of its Being, we shall denote by the term 'Dasein'*" (Heidegger, 1962/2012, 27).

Dasein means "*to be there, to be here*" and for "*Heidegger is a way of referring to the human being as well as the type of 'Being' that humans have*" (Inwood, 1997, 22). Dasein appears to be a term for existence with meaning, a life force that is able to intuit its own existence and question why. Heidegger argues that, as beings, we are concerned with our being-in-the-world, which he hyphenated to denote the inseparability of being in and of the world around us (Miles et al., 2013). His idea of the lifeworld is that it forms part of us and we the same of it. In this respect, Heidegger moved away from a focus on the consciousness towards a more embodied being-in-the-world. "*The life-*

world is disclosed by Dasein not as a realm of neutral things or objects ... but rather as the referential totality of Dasein's own direct involvement, as a realm of possibilities upon which it has already projected itself" (Wollan, 2003, 32). For Heidegger, Dasein is not just individual existence; it is co-existence through inter-subjectivity, history and space. *"Heidegger's phenomenology attempts to address the situatedness of individual's Dasein in relation to the broader social, political and cultural contexts"* (Wojnar and Swanson, 2007, 174); people are enmeshed in their life-world, created by it and not just an observer. Sheehan (2013, 388-389) proffers that Heidegger's being-in-the world, is often misunderstood as standing within a world of *"spatio-temporal things out there"*. Rather, he sees Heidegger's "world" as the relatedness of human understanding, i.e. the giving of meaning to everything we encounter. Likewise, he argues that *"in"* refers to our a-priori involvement with the meaning process, suggesting a better interpretation of *"being-in-the-world"* might be *"engagement-with-meaning"*.

Heidegger perceived that there is no fixed existence, no fixed being, rather being is time and time is never simply present (Finlay, 2011). According to Heidegger, the cornerstone of Dasein is time, with an attachment to time and space in the memory, body sensation and the spirit of an experience. This is linked to culture and history, which also helps to provide understanding and beliefs. *"The experience of time and space is also not a situation-less experience; we are locked in our own temporo-spatial context, because of always being-in-the-world"* (Miles et al., 2013, 411). According to Heidegger, our condition is always *"becoming"* as we project forwards, intentionally *"ahead"* of the subject and considering possible meanings related to the subject. *"We ourselves are structurally ahead in the possible, right up to the possibility of our own death"* (Sheehan, 2013, 388). Yet, who we are as a person builds from our past (Finlay, 2011).

The being of things is never fully before us. We go about our business without the need to regard the chair we sit on while typing, or the desk

our forearms rest upon. Only if the chair breaks suddenly, does it enter into our view. Only if the computer develops a fault, do we suddenly peer upon its form and wonder more deeply about it. Whilst it works toward typing our letter, the computer remains invisible to our directedness. Heidegger suggests that objects which hide from our view in this way are the past; on the other hand, objects which enter our view for interpretation are the future. Together, these two dimensions create *“the present”* and a *“world that is a constant back and forth between shadow and light – and this endless passage is called time”* (Harman, 2007, 2).

According to Heidegger, we are born into a world that already exists and carried along by its momentum, as we grow. From a babe in arms, unable to control our environment, we are passed through life by other humans, constantly thrown towards our future. Heidegger terms this Dasein’s *“thrownness”*, which we can never step away from or outside of, to see the world truly objectively (Bolt, 2011). Already, one may be able to appreciate the strength of this trajectory in a family orientated culture, such as farming. When the men say: *“I was born and bred a farmer”*, they really were in their thrownness towards this lifeworld. Although we can choose our friends, we do not have a choice about the place of our birth or the trajectories our lives take, in the early years, and how this affects us latterly. One could envisage that a young boy born into a farming family in Hereford would be socialised to see many opportunities related to farming, but not, for example, so many as a member of a whaling fleet off Japan. The emphasis on his relationships might be towards maintaining the family farm, rather than residing in a Buddhist temple. Heidegger calls this array of factors which take into account our current life circumstances and our future possibilities, *“facticity”*. *“Facticity relates to the possibilities that our ‘thrownness’ enables, and how the sum total of our existing situation sets up or opens up future possibilities”* (Bolt, 2011, 175). Being-with-others is part of our thrownness. As we grow, our interaction with others helps us to adopt the values and expectations of the society to which we

belong. The problem for Heidegger was that being with others can dissolve one's own Dasein, for a Dasein of the "they", which he argues leads to inauthentic lives.

"Dasein is not an isolated being, rather it relates to the world through the interaction with others" (Miles et al., 2007, 411). Heidegger states that it is "care" (*sorge*) for life that provides the connectedness required to engage in the world or in another's life-world. Harman (2007, 29) argues that this care is what enables us to make meaning:

"Even more generally things have meaning only because human Dasein has the structure of care. This means that human beings always take a stand within the world ... we do not primarily look at the world like neutral observers, but care about what happens in it".

Heidegger also introduces us to the idea of fallenness. Fallenness is the universal tendency of human beings to lose themselves in the everydayness of present concerns and preoccupations, to such a degree that it *"alienates them from their personal and unique future possibilities"* (Mills 1997, 66). This then relates to how we live our life and portray it to others, in an authentic or inauthentic way. The modes of being of Dasein may be either authentic (taken up as one's own) or inauthentic (determined by outside forces such as family and the wider society). Authentic existence involves an element of choice not found in inauthentic existence. We move from the authentic moment to the inauthentic, as we traverse through life: *"this double edge is Dasein"* (Mills 1997, 65). As Mills (1997, 42) argues: *"not only does Dasein unveil itself in the mundane modes of daily existence, but it does so in a false manner"*. This is linked to our selfhood and its state of authentic or inauthentic disclosedness. As we move through life in our fallenness, we adopt both these states in our interaction with others. Critics of Heidegger argue that his concepts neglected the role of the body and how it *"participates in shaping our everyday understanding of things"* (Aho, 2009, 3). Aho (2009, 1) states that Merleau-Ponty laid the

first foundations for an embodied account of the lifeworld, related to the *“primacy of bodily perception, particularly in terms of our spatial directionality and orientation”* within the world. It is to Merleau-Ponty I will next turn my attention.

4.6.4 Merleau-Ponty: The Body and World

Maurice Merleau-Ponty (1908-1961) was a French phenomenological philosopher, strongly influenced by Heidegger and his predecessor Husserl. In his *‘Phenomenology of Perception’* (first published in 1945) Merleau-Ponty introduced the philosophical concept that perception is a bodily phenomenon which manifests itself as an aspect of our bodily being in the world. This is not a Cartesian perspective, but follows on more from Heidegger’s *“to be”* is *“to be of the world”*. Merleau-Ponty considered that *“perception is both intentional and bodily, both sensory and motor, and so neither subjective or objective, inner or outer, spiritual or mechanical”* (Carman, 2008, 78). He strived to provide a phenomenology of the body, just as Husserl had tried to do with the mind, one that is free from scientific rhetoric, a first-person view of the experience of the body *“as it informs our intuitive sense of perceptual sensitivity and agency, oriented and open on the world”* (Carman, 2008, 93). This involves an understanding of body intentionality, as it is embedded in the world; Carman (2009) terms this the bodily point of view. From the bodily point of view we *“understand ourselves as neither disembodied intellects nor physical mechanisms but living bodily subjects”* (Carman, 2009, 132). In his book, *‘The Visible and the Invisible’* (published 1968), Merleau-Ponty also introduces us to the metaphors *“chiasm”* and *“flesh”*, in an attempt to describe not only our bodily embeddedness in the environment, but our unconscious bodily continuity with the world. *“As bodily perceivers, we are necessarily part of the perceptible world we perceive; we are not just in the world, but of it”* (Carman, 2008, 133). Chiasm relates to this intertwining of body with others and with our landscape. Flesh is not the flesh of the body, *“it is the coiling over of the visible upon the seeing body, of the tangible upon*

the touching body, which is attested in particular when the body sees itself, touches itself" (Merleau-Ponty, 1968, 146); it is our living connectivity to the world. Importantly, for Merleau-Ponty, how one experiences their own body necessitates how a person experiences the surrounding world. For instance, a negative view of a part of my body, its look or function, may consciously or unconsciously enter into my appraisal and experience of my environment; hence, the body is also our source of spatiality (Gallagher, 2005). *"For Merleau-Ponty, the structure of lived space emerges from a relationship to our environs that is both perceived and produced through the activities we engage in"* (Davidson, 2000, 644); thus, lived space is mediated through our bodies.

Merleau-Ponty argues it is through our body and not our minds that we learn to understand our world and cohabitate with others (Carman, 2008). He terms this our body schema: *"A child is able to acquire specific bodily and social skills by watching others ... his body is innately attuned and socially habituated, hence prone to act as others are visibly acting"* (Carman, 2008, 144). Merleau-Ponty regards others as neither visible objects, nor invisible subjects, but rather bodily agents in which he infers the existence of other minds, by observing their bodies and recognising behaviours that are his own. During discussions about my study with the CR receptionist (who is also a farmer's daughter and now wife) she reminisced, how as a child, along with her other siblings, they were expected to help to get the harvest in, or herd the sheep. One can imagine this transference of body style, movement and knowing how to physically do the job, from the adults to the children. This is a good example of the intertwining of the corporeal and intercorporeal with others and world.

As with Heidegger, Merleau-Ponty also considered temporality integral to existence, stating that all our experiences are temporal, in that they arrange themselves in terms of a before and after. However, time is not a real process, but arises from our relation to things and exists in unison of itself:

“A past and a future spring forth when I reach out to them. I am not, for myself at this very moment, I am also at this morning or at the night which will soon be here, and though my present is, if we wish so to consider it, this very instant, it is equally this day, this year or my whole life” (Merleau-Ponty, 1962/2010; 489).

4.6.5 Gadamer: Language and Interpretation

Hans-Georg Gadamer, a philosophy student at Marburg and Freiburg, in the early 1920s, was also influenced by the work of Husserl and Heidegger (Lavery, 2003). Over time, he allied himself more to the work of the latter and looked to extend it in a practical sense. He recognised, like Heidegger, that language and understanding are integral and inseparable aspects to being-in-the-world, and indeed that understanding and interpretation are also bound together. His importance here lies in his development of hermeneutic philosophy. Hermeneutics, *“the art of interpretation”* was not a method for understanding; rather, Gadamer saw it as an attempt *“to clarify the conditions in which understanding takes place”* (Gadamer, 1975/2004, 263). In his book, *‘Truth and Method’* (first published 1975), he too is critical of the modern sciences’ approach to the humanities, arguing that *“truth”* and *“method”* were at odds with each other through their adoption of scientific methods. Gadamer argued that truth is not reducible to a set of criteria, promoted by science. He also claims that people have a historically effected consciousness, shaped by their history and culture, which shapes how we interpret the world:

“Long before we understood ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society, and state in which we live. The focus of subjectivity is a distorting mirror. The self-awareness of the individual is only a flickering in the closed circuits of historical life. That is why the prejudices of the individual, far more than his judgments, constitute the historical reality of his being.” (Gadamer, 1975/2004, 440)

In this way, when a person reads a text, they can only understand it if the words and meanings articulate with their own background, in some way. The reader's own prejudices, pre-conceptions, fore-meanings and evolving history will influence how an object (text) is understood and interpreted. Gadamer (1975/2004, 296) states: "*the meaning of text goes beyond its author*", i.e., when one reads a text understanding is not merely reproductive, but productive, evolving and different every time:

"Understanding is not, in fact, understanding better, either in the sense of superior knowledge of the subject because of clearer ideas or in the sense of fundamental superiority of conscious over unconscious production. It is enough to say that we understand in a different way, if we understand at all" (Gadamer, 1975/2004, 296).

Gadamer argues that in attempting to transcend any pre-conceptions regarding the subject, as one is instructed to do from a Husserleian viewpoint, the researcher in essence remains anchored to their past: *"By claiming to transcend its own conditionedness completely in knowing the other, it is involved in a false dialectical appearance, since it is actually seeking to master the past"* (Gadamer, 1975/2004, 354). According to Gadamer (1975/2004, 270):

"understanding realises its full potential only when the fore-meanings that it begins with are not arbitrary" and "the important thing is to be aware of one's own bias, so that the text can present itself in all its otherness and thus assert its own truth against one's own fore-meaning" (Gadamer, 1975/2004, 271-272).

I will discuss some of the issues related to phenomenological reduction versus a more open stance towards researcher bias in the next chapter.

4.7 Summary of the Chapter

This chapter aims to explain the philosophical foundations upon which this study stands. The Farm Angina Project utilised qualitative

research, seated within an interpretivist epistemology and ontology, employing a discursive qualitative approach, namely hermeneutic phenomenology. It was undertaken in this way to answer the question: *“How do farming dyads experience SAP?”*

An overview of relevant historical layers pertinent to this study are given, with Husserl’s formulation of the concept of lifeworld and Heidegger’s notion of being-in-the-world. Following on from these, the work of Merleau-Ponty is introduced, with his focus upon the body concept and notion of extended corporeality. I refer to the hermeneutic writings of Gadamer, who helps to bring the other elements together, through his interpretation of the importance of language and understanding.

The next chapter describes the methodology that helps to bridge my philosophical stance with the congruent methods chosen to conduct this study. This includes consideration of the relationship between phenomenology and the study of pain / illness, culture and some exploration of the idea of existential mood, as a backdrop to the study.

Chapter Five: METHODOLOGY

“who is my body
that now fears the open fields
and silent mornings?”



*“I suppose if I am honest I have got a deep seated fear of getting ill up
here and being isolated...that is always at the back of my mind, what
if?”*

Kevin

5. Chapter Five: METHODOLOGY

5.1 Introduction

This chapter details how hermeneutic phenomenological methodology shaped my practical approach to: (i) participants and where, as well as how, I conducted interviews; (ii) my own embodied experiencing and its relevance within this type of study; (iii) data gathering, management and interpretation; and (iv), writing style, with a commitment to first-person dialogue and creative expression.

The aim is to demonstrate congruence throughout, consistent with a hermeneutic phenomenological research paradigm. To begin with some consideration of the relationship between phenomenology and pain / illness, and how this relates to existential suffering and wellbeing is undertaken. I will then discuss the notion of culture from the same perspective, before exploring the idea of existential mood. All these are important facets pertaining to my methodology and how this was applied practically to data gathering and analysis in order to understand how farming dyads experience SAP.

5.2 The Phenomenological View of Pain and Illness

Morrissey (2011, 18) describes the current thinking on pain as a “*conceptual swamp*”, due to a scientific desire “*to demarcate too clearly the margins of bodily and non-bodily pain and suffering ... and by failing to recognise that pain and suffering are distinct phenomena*”, where each can be present without the other. The author argues that a prevailing Cartesian philosophy and medical model of treatment too easily dichotomises pain and suffering into body / mind dualisms, instead of seeing each as a lived through experience, requiring phenomenological enquiry. Despite this, a biopsychosocial conceptualisation of pain is now the accepted norm, with regards to clinical management and investigation, recognising with this approach

the overlapping biological, psychological and social dimensions that contribute to pain's manifestation and effect on personal wellbeing (Hadjistavropoulos et al., 2011). This model was first presented in 1977 by George Engel (Engel, 1977) and was hailed a landmark concept, detailing for the first time the dynamic interaction of the three elements described. However, in palliative care, there already existed the notion of "*Total Pain*", first used by Cicely Saunders in the 1960s. This concept was developed from patient narratives, and brought together notions of the physical, social, psychological, spiritual and temporal dimensions of pain (Gunaratnam, 2012). As much a practical approach to care of the dying, as a philosophy, Saunders reasoned that pain should be treated as a situation, rather than an event, with equal attention not only to the body, but to the family of the sufferer, as well as their inner life:

"Saunders argued that the constituency and temporality of pain had to be approached as a complex heterogeneity that included not only the physiological but also the social, economic and existential, so that the focus shifted from the genre of disease, and from biochemistry and drugs, to treating the many symptoms ..." (Gutaratnam, 2012, 115).

It is argued that phenomenology gives us the opportunity to view pain in the wider context of embodied health monism, a perspective that emphasises the unity of "*mind-body-world*" (Ghane and Sweeny 2012; Bullingham, 2009). Phenomenology rejects the naturalistic view of illness, one based on objective physical findings and explained from a neutral, third person perspective. Instead, it seeks out the first person "*lived experience*" of, in this case illness, against a backdrop of everyday life.

Goldberg (2012, 837) also argues that the treatment of pain can only gain from phenomenological study of sufferers' lived experiences, an approach that remains somewhat incongruent to current clinical perspectives: "*... attending to the lived experiences of a person's pain centres the sufferer as subject, which matters because pain is the quintessential subjective phenomenon*". Phenomenology presents us

with the opportunity to understand human experience, including pain, in the context of the subject's lifeworld and therefore is able to take account not only of the individual's understanding of their situation and its meaning, but also the inter-subjectivity of human experience; the shared meanings that are the basis for social interaction and how pain affects perceived freedom within these worlds. Phenomenologists seek to understand how people experience their pain in the existential context of their lives and how such suffering bestows meaning (Honkasalo, 2001). This involves the delicate interplay between the lifeworld existentials of lived body, lived space, lived time and lived relations; for, as Geniusas (2013, 8) states: *"the lifeworld is the soil in which our pain grows"*.

5.3 Existential Suffering and Wellbeing

Linked to the idea of pain / illness from a phenomenological perspective is the concept of existential suffering and wellbeing. Galvin and Todres (2013, 72) express existential wellbeing as being able to *"access to one's existential possibilities in time and space, with one's body and with others"*. In this respect wellbeing should not be confused with health or wellness, words that are often used interchangeably. Neither is wellbeing happiness, it is more than that, and yet a succinct definition is elusive (Healey-Ogden and Austin, 2011). Healey-Ogden and Austin (2011, 93) explored what a lived experience of wellbeing entails. They concluded:

"We found wellbeing to be inherent in life and therefore lived. We discovered that coming to experience wellbeing arose from being open to this phenomenon in a space where people embraced the wonder of the moment and of their connections with life in and around them. The lived experience of wellbeing was in their dwelling and moving forward on the journey toward and within this space."

Wellbeing then is *"a way of being-in-the-world, as well as how this way of being-in-the-world is felt as an experience"* (Galvin and Todres, 2013, 75). It is the fulfilling of one's own Dasein by living authentically with

what you have been given and the possibilities of one's thrownness. When this is challenged existential wellbeing can become existential suffering.

Galvin and Todres (2013) offer 18 categories of existential wellbeing and suffering based on the lifeworld constituents of Husserl and Heidegger; spatiality, temporality, intersubjectivity, mood and embodiment (see Appendix L).

The suffering and wellbeing framework proffered by Galvin and Todres (2013) is based on the interplay between existential dwelling and mobility. The authors give two definitions for these interrelated states;

- Mobility – *“The essence of mobility lies in all the ways in which we are called into the existential possibilities of moving forward with in time, space, others, mood and our bodies. The feeling of this moving forward is one of energised flow”* (Galvin and Todres, 2013; 76).
- Dwelling – *“The essence of dwelling lies in all the ways that we existentially come home to what we have been given in time, space, others, mood and our bodies. The feeling of this coming home is one of acceptance, rootedness and peace”* (Galvin and Todres, 2013; 76).

According to the authors, “dwelling” and “mobility” are not separate states, the experiences of each can be found in unison whilst remaining discretely different; *“The nature of embodied experience is that it is able to hold multiple qualities at the same time”* (Galvin and Todres, 2013; 79). The definition of existential wellbeing that Galvin and Todres (2013) present us with then is an amorphous, temporal entity. It is never one thing but a tension between states, a movement back and forth between dwelling and mobility, between wellbeing and suffering, fluid and constantly changing. The interplay of the lifeworld existentials (embodiment, spatiality, temporality, inter-subjectivity and mood) offer subtle nuances and emphases which guides the shape such existential wellbeing takes.

It can be argued that by offering some categorisation of the layers that make up existential suffering and wellbeing Galvin and Todres (2013)

give us an opportunity to understand how illness might effect a person in a more nuanced way. I decided that consideration to suffering and wellbeing in relation to SAP, was more appropriate to the design of my study than the idea of 'pain' alone, as this did not adequately describe the effect of SAP on participants' lifeworld's. Hence my decision to refer to the suffering and wellbeing definitions offered by the authors in their "lattice" in my interpretation of participant journeys.

5.4 Culture and Phenomenology

I found it unclear to begin with whether culture is a feature of phenomenological ethos or not; yet, in my decision to interview farming couples, I had already let-it-be-known my view that it is integral to a person's experiences. As Demerath (2002, 208) states:

"The desire to know our environment motivates us to create and maintain culture. By sharing our interpretations with others, we verify, strengthen, and expand our understandings of our environment. In doing so, we create consensual meanings and, thus, culture".

Here, she is linking meaning-making and subjective experiences with the culture to which a person is allied and helps to maintain. Demerath (2002, 208) also argues that a person needs a cultural identity, to help make the world subjectively meaningful and *"enhance their sense of security in the world"*. The author states that *"culture is epistemological because it makes our experience understandable, and makes us feel as if we know the world and our places in it"*.

Clucas (2000, 11) concedes cultural phenomenology might not fit with Husserl's notion of lifeworld and its *"pre-conceptual world of intuitive lived experiences"* or Heidegger's view of authentic Dasein, before the *"they-self"* of living amongst others inauthentically. However, he suggests that cultural phenomenology could be *"an investigation of what is not intended (or attended to) in culture: to make the givenness and obviousness of culture conspicuous by aesthetic presentations"*

(Clucas, 2000, 27). Thus, the multiplicity of lived experience and everyday phenomena can then be allied with history and culture.

Merleau-Ponty, did not see phenomenology as a-cultural (Felder and Robbins, 2011), recognising the importance of personal and cultural contexts in the formulation of perception. Merleau-Ponty argues that culture provides “*available meanings*” that are the basis for language and creation (Felder and Robbins, 2011). Felder and Robbins (2011) consider this in relation to the loss of body function and how this would impact upon one’s place in a certain culture. The authors argue: “*if the existential structure of one’s existence consists of maintaining an identity based on a mosaic of intact body powers which link one to a particular cultural world, then the loss of bodily powers threatens to create a tear in the intentional threads tying a person to the flesh of a meaningful world*” (Felder and Robbins, 2001, 11-12). Certainly, this resonated with me with regards to the SAP suffering farmers in my study, whom I perceived may experience this rupture between body self and world.

Gadamer was also keen to emphasise the importance of history and culture in all understanding (Langdridge, 2007). For Gadamer “*understanding is not about producing a-historical and a-cultural truths about the world – the project of science – but rather something that is situated in a particular space and place, historically and culturally contingent*” (Langdridge, 2007, 42).

Hermeneutic phenomenology recognises that experience is “*embedded in a particular culture and as having a particular meaning based on the concepts and values of that culture*” (Carel, 2011, 35). It was important, therefore, to gain a view of the participants’ history and culture, in order to better understand their SAP experiences. Integral to the study was the fact that farming is a particular kind of lifestyle, culture and heritage (Price and Evans, 2009) and that this appeared to influence their health needs (Syson-Nibbs et al., 2005); so, to ignore this would have, in my opinion, been a mistake.

5.5 Existential Mood

The importance of “mood” became apparent to me during interviews and then, again, at the stage of data analysis. Although I did not incorporate it as a category for data analysis, it emerged out of the four existential dimensions during stage two of the process (see Figure B.). Heidegger (1962/1927) claims that we have three constitutive ways of disclosing our being-in-the-world: discourse (rede), understanding (verstehen) and Befindlichkeit, or according to Stolorow (2013) “how-one-finds-oneself-ness”, which shows up as a deep mood, below more transient moods, but influential upon these.

According to Fuchs (2013, 224): *“Moods are atmospheric in nature, radiating through the environment like warm or cold, and conferring corresponding expressive qualities on the whole situation”*. I recognised this during the fieldwork stage of my research. There was an overarching “sense”, or atmosphere that accompanied both words spoken, during interview, as well as the spaces in-between. I experienced this was an embodied feeling. Fuchs (2013, 224) states: *“These background feelings are not just related to an anonymous world, but to the world we share with others, or the interpersonal world. They are existential feelings of being-with”*.

According to Kenaan and Ferber (2011, 4): *“our embeddedness in the world, our basic attachment to meaning, finds its primary expression in the experience of the world as that which matters to us: in moods”*. Moods then are world-revealing. Heidegger argues that moods precede cognition as a primordial sense of being: *“every feeling is an embodiment attuned in this way or that way, a mood that embodies in this or that way”* (Heidegger, 1961/1979, 100). Indeed, it is mood that conditions the primacy of our body, the way we think, feel and express our self, through posture and movement, about a subject.

“The possibilities of disclosure that belong to cognition reach far too short a way, compared with the primordial disclosure belonging to

moods, in which Dasein is brought before its Being as 'there' (Heidegger. 1961, 173).

Mood allows us to experience the world in an unintentional wholeness, which colours how we see the world and through which thoughts and actions operate. Hence, if I am anxious, my thoughts may feel hurried, confused even, my body movement stiff, staccato and the world seem a threatening place.

Ratcliffe (2013, 171) argues that mood should be replaced by the term “*existential feeling*”, reasoning that how we find ourselves in the world incorporates changed bodily perception. However, Aho (2009, 26) argues that “*moods disclose a basic temporal structure of Dasein, the structure of 'alreadiness', that is prior to my own embodied agency*”. Aho (2009, 26) considers that moods already exist in the world and, as such, we grow into them: they are “... *'like an atmosphere' already there prior to the emergence of the body*”. These conflicting viewpoints highlight the differences of opinion which surround Heidegger's perception of mood and the primacy of the body, or lack of it. In relation to supporting this study's findings, I concur with Ratcliffe's viewpoint of embodied mood. In this respect, Fuchs (2013, 224) argues:

“Moods may be said to tune body, self and environment to a common chord, similar to a tonality linking a series of notes and chords to the major or minor key. Thus they tend to establish a consonance of bodily feeling, emotion, and environmental atmosphere” (Fuchs, 2013, 224).

Husserl argues that our default attitude is a habitual sense of certainty – “*a non-propositional, bodily, practical trust in the world*” (Ratcliffe, 2013, 607). However, there are felt, intentional attitudes that can run contrary to this, which cause the individual to feel doubt. I decided that further consideration of this notion of existential trust related to my findings was required based on what I had sensed and evidenced within participant narratives.

5.6 Approach to Participants

Hermeneutic Phenomenology acknowledges that interaction with others is co-constructed dialogue and understanding. It is important when following this approach that one considers how research interviews might take shape and the influence a researcher brings to them. Thus, a measured and reflective standpoint can be reached, where one's own pre-suppositions and beliefs are recognised and considered as part of data collection (Van Manen, 1990). Finlay (2011) outlines four key stages of hermeneutic phenomenological research approach, which I replicated within this study: (i) A participant's description of any lived experience must be viewed in the context of that person's life situation and projects; (ii) Interpretation is further indicated by the belief that researchers can never be impartial to the data they witness; (iii) All interpretation is influenced by whatever contemporary ideas the researcher espouses; (iv) Research findings arise out of a co-created dialogue which takes place in a particular, shared space.

A commitment to embodied interpretation as advocated by Galvin and Todres (2013) and creative writing approach (Van Manen, 1990) were also primary tenets of this particular hermeneutic phenomenological study.

5.6.1 Inter-subjectivity and Understanding

According to Packer and Addison (1989, 33), one of Heidegger's foremost contributions to philosophy and science was his notion of a circularity of understanding. When studying a new phenomenon, we are thrown forward into it; we make assumptions about it based on our own "*fore-structures*" made up of expectations, preconceptions, our lifestyle, culture and tradition. In this way, we might better understand, or indeed be mistaken about, the phenomenon based on these projections. The circle of understanding is not vicious or closed; otherwise, no learning would be possible. Although we understand,

based on what we know, we also accommodate and assimilate new information, changing the basis of our own fore-structures, as we do so.

We exist alongside other human beings, and perceive each person as that, not just an object in our horizon of view. From childhood, we are attuned to others in a form of “*immediate sympathetic harmony*” (Carman, 2008) watching and mirroring the actions of those around us, obtaining specific culturally-led bodily and social skills. These experiences form an important background to adult consciousness. This enables us to empathise with fellow humans and place ourselves in their situations, which Husserl termed “*appresentation*”. Understanding another through indirect appresentation is summarised by Dahlberg et al. (2008, 61) as “*through imagination and by comparing others behaviours, expressions, gestures, etc. ... with how we think that we would think, feel or be in their place, we come to understand something of them*”. Consideration of appresentation was important to me, as part of the study involved asking participants about their partners. It was presumed that within their replies descriptions based on appresentations of their partners’ experiences would be made. I was interested to see how each partner saw the other’s life affected by SAP, and whether there were similarities or otherwise in dyads’ recollections.

Empathy in these terms, therefore, is an evolved, biological capacity of the human species to understand other humans (Thompson, 2009) that provides us with some understanding of others’ minds, although it still has limitations. Others can also fake or conceal their experiences, making our appresented view of them and their actions inaccurate. However, as Ashworth argues (1996; cited in Finlay, 2009), it is not the role of the phenomenological researcher to argue the truth or falsity of participants’ narratives, but to take what they say as “*that*” which is being offered.

5.6.2 Language

Language also shares this intertwining of world, empathic understanding of others and self; within us, it provides the narrative of our thoughts and without helps us to communicate what is within us to others. Language allows us to negotiate with others what is objectively real around us, judging things to be so when others confirm our perceptions. This confirmation exists both within us and joins us with others in a public declaration of understanding. *“The objective real is what is there for all of us. It has an inter-subjective presence ... such verbal agreement is our touchstone for the real”* (Mensch, 2010, 453). Therefore, where no verbal agreement exists, there may be differing and diverging perceptions of what is real. Again, this affects one’s ability to empathise with and appresent to another person.

Gadamer believes language, especially conversation, is at the heart of all interpretive understanding and that central to such understanding is self-understanding: *“... we always speak from somewhere, from a position dependent upon our history and culture”* (Langdrige, 2007, 42). He argues that, in the act of interpretive understanding, both parties are changed: *“To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one’s own point of view, but being transformed into a communion in which we do not remain what we were”* (Gadamer, 1975/2004, 371). I needed the participants to speak to me as authentically as I could facilitate; therefore, the use of language was an important factor. Prior to the fieldwork, I discussed my concerns about effectively interviewing farming couples with our onsite farmer’s wife / daughter and CR Secretary. We rehearsed how I could best approach couples. Reducing medical terminology, speaking clearly and plainly, and starting the conversation with a subject participants may feel most comfortable speaking about, e.g. the farm, became my adopted tactics. Thus, I hoped to promote productive ‘communion’.

5.6.3 Pre-understanding, fore-projection and prejudice

In line with a hermeneutic phenomenological approach I needed to understand my own positioning as I commenced my study fieldwork. In some ways, having no experience of farming allowed me to position myself naively and openly before couples. I also considered guidance offered by Gadamer:

- *Pre-understanding and fore-projection*, Turner (2003) – explains that from a Gadamerian perspective, understanding does not come from being a neutral observer, but through the intimacy of understanding that occurs as part of a hermeneutic circle. Understanding occurs as we circle from the whole to parts of the subject, to the whole again. During this circle (or spiral), we must acknowledge that our pre-understanding and fore-projections will have to be revised and that we must demonstrate willingness to embrace different, more universal points of view.
- *Prejudice* – during this circular interaction, prejudices are formed. Gadamer suggests that rather than believe these are false judgements, they should be treated as a condition of truth, which may change over time. We should strive not to eliminate them, but to understand why they have occurred, try to discriminate between them and accept them as conditions of our understanding of a phenomenon (Turner, 2003).
- *Fusion of Horizons* – Gadamer states that our horizon is something that moves with us, rather than something into which we move. A fusion or horizon occurs when a person understands another's; when there is a conscious act of fusing two or more horizons, historical consciousness is achieved (Conroy et al., 2003).

By accepting Gadamer's notion of a fusion of horizons, I also recognised that what I would be allowed to observe within others' landscapes would be censored. Each participant maintained the freedom to conceal aspects of their lives from me; such as the female participant who did not reveal that she had left her partner briefly. It

was only during the follow-up interview with her spouse that I learnt of this occurrence. I was required to take a step back and recognise that this was something she was not prepared to share about her life, although undoubtedly an event of some significance. I could not “*unhear*” what her partner had told me and therefore some degree of influence over her narrative must have taken place, although I attempted to hear only her “*truth*” as I moved to analysis.

I could also be mistaken about the meaning of what was said (Packer and Addison, 1989); this may occur because participants use phrases and terminology that are not common to my own, particularly as I don’t hail from a Herefordshire farming background and so do not share a similar local history or culture.

5.6.4 Embodied experiencing and interactions

As a physiotherapist, I was influenced by Les Todres (2007) and his development of embodied enquiry. His descriptions of a bodily sense and understanding struck me as a phenomenon I had already experienced, but never articulated. I decided early in data gathering to attempt embodied enquiry. This would mean acknowledging the shared space with participants, recognising that communication is not just through language alone, “*that it needs a body and more*” (Todres, 2007, 23); also that “*in this relationship of mixing and separating that language, embodiment and the ‘more’ are intimately related, and as such cannot be reduced to one another*” (Todres, 2007, 23). This “*more*” that Todres relates to is the embodied sense of what a meeting is about. A participant might describe being happy, but the manner in which this is spoken, their body language and the embodied sense of the moment, might point to “*sadness*”. The “*more*” is the whole of this situation, carried by the body. This does not mean that their words should not be believed, but some context is possible. Hence, I decided that it was important to log such experiences.

Todres (2007, 3) states that, with regard to research methodology, *“embodied understanding is not just ‘cognitive’, but involves embodied, aesthetic experience and application”*. My commitment to acknowledge my embodied knowing during field-work was decided.

Merleau-Ponty describes inter-subjectivity as *“a bridge between my self-acquaintance and acquaintance with others”*, in which one’s embodied subjectivity has an exteriority. That *“embodied self-awareness as a presentiment of the other – the other appears on the horizon of this self-experience – and the experience of the other has an echo of one’s own bodily constitution”* (Zahavi, 2001, 163). Gendlin (1992, 342) agrees with Merleau-Ponty, arguing that bodily interaction exists, prior to linguistic communication, which continues during and after language:

“Our bodies sense themselves in living in our situations. Our bodies do our living. Our bodies are interaction in the environment; they interact as bodies, not just through what comes with the five senses” (Gendlin, 1992, 344).

It was important for me to realise that my embodied understanding of my participants was reciprocal, and how they perceived me would influence our subsequent discussions and their disclosedness. Indeed, King et al. (2008, 92) argue that *“there is an implicit Cartesian dualism in assuming that what is produced in an interview comes from within the research participant”*; interviews are in fact co-constructed by all those involved.

5.6.5 Place and space of interview

Integral to consideration of embodied understanding, I also needed to consider spatial influences. Elwood and Martin (2000, 649) argue:

“The interview site itself embodies and constitutes multiple scales of spatial relations and meaning, which construct the power and

positionality of participants in relation to people, places and interactions discussed in the interview”.

Certainly, by giving my participants the choice of interview location (home or at the hospital) the same authors suggest that interviewees may then feel more empowered during discussion, hence speak more confidently and candidly about their experiences. Alongside what I thought would be a better recruitment strategy, the decision to interview participants in their own homes was made; this was to improve the authenticity of discussion, which may have been threatened by less unfamiliar surroundings.

Space and time were important facets, not only with regard to the content of discussions, but how they affected conversations and my own subjective and embodied sense of my meetings with participants. Travelling out to unfamiliar parts of Herefordshire, leaving recognised roads for dirt tracks, in some cases, negotiating dogs in farm-yards, sitting in cluttered kitchens, while the snow fell outside, and meeting these private souls in the brightness of midday and darkness of a winter’s night had a marked effect upon me, which I still find difficult to articulate. However, I felt it important to represent this aspect of the study, during the formulation of findings, as it ties in with my embodied data recollections.

5.7 Data Gathering, Management and Interpretation

As Cohen et al. (2000) state: *“the goal of (hermeneutic analysis) is a thick description that accurately captures and communicates the meaning of the lived experiences for the informants being studied”*. However, Guigan (2012, 99) cautions that hermeneutic phenomenology *“challenges the assumption that empirically discoverable generalisations about casual relations can be discerned in the study of humans. It holds, instead, that since humans are ‘sense-making’ or ‘self-constituting’ beings, there is no reason to expect to find fixed, unchanging regularities underlying their behaviour”*. Recognition that

the information shared would be a tangle of contradictions, backtracking and confusion was a pre-requisite of my positioning as a hermeneutic phenomenologist. Rather than trying to reconcile the many discrepancies, I needed to highlight them, as a condition of understanding the complexity of humanness. Integral to shaping data in a way that was congruent with my approach was my utilisation of the hermeneutic circle, bridling of scientific pre-conceptions and consideration of literary style to report my findings.

5.7.1 The hermeneutic circle

Key to hermeneutic phenomenological analysis is a keen sense of the “hermeneutic rule” of understanding, i.e. being able to perceive the whole of a phenomenon under investigation, in terms of its detail, and the detail in terms of the whole. As Dahlberg et al. (2008, 237) state: *“the train of thought between the whole – the parts – the whole is an important part of the hermeneutic tradition and the idea of a hermeneutic circle is still applied as a principle ... of how to understand the meaning of the data”*. Cohen et al. (2000, 73-74) argue that use of the hermeneutic circle means interpreting data in which *“the smallest statements must be understood in terms of the largest cultural contexts”* and vice versa. They argue that a hermeneutic phenomenological approach *“involves moving away from the field text, created by data collection, to a narrative text that is meant to stand alone for other readers”* (Cohen et al., 2000, 76).

The hermeneutic circle has a sense of infinity about it, as it is acknowledged within hermeneutic phenomenology that there is no absolute truth, but many interpretations and stages of truth. One can only reach a place of sensible meaning (Miles et al., 2013). Throughout the analysis, this movement from the whole to the specific and back again was a constant motion. As themes and interpretation began to take shape, these were repeatedly taken back to the whole, including my embodied sense of data gathering, to question their validity and

relevance. Slowly, understanding took shape and out of that came interpretation.

It was as I entered the hermeneutic phenomenological circle, and began to learn about the worlds of farming couples, that I also began to understand my own predispositions to perceiving them. For example, I held an assumption that those who perceived their SAP as damaging to their heart would probably cope less well on the farm, than those who did not. Certainly, there is research which supports this notion (Furze et al., 2005). However, this was not always the case; other elements of their lifeworld tempered this ability to cope, which I was not aware of before starting the study, e.g. space and the farm landscape offered both protection from prying eyes, yet also fear linked to feeling isolated. This made me re-examine the fore-structures of my understanding, their effect on my interpretive account and the need to become more open in attitude. Otherwise, the study would risk becoming a record of my own pre-understandings projected on to the participants' narratives. This realisation led me to consider the notion of phenomenological reduction.

5.7.2 Phenomenological reduction

Finlay (2009) states that most phenomenologists agree there is a need for an open attitude when engaging with participants; however, disagreement exists as to whether it is necessary to engage in reduction and, indeed, what this might involve.

Husserl believed that the mind is always directed to objects, terming this directedness "*intentionality*". He postulated that the phenomenologist needs to be focussed on both the manner of being aware of something ("*noesis*"), as well as the objects of this awareness ("*noema*"), as we experience them (Finlay, 2011, 45). To do so, he asks researchers to bring a specific attitude to bear involving reduction: *"In this reductive attitude, phenomenologists rigorously 'bracket' past/theoretical knowledge and abstain from positing the existence of*

the natural world around us" (Finlay, 2011, 45). Phenomenologists are then asked to dwell with the experiences being viewed, in order to discover emergent patterns of essences and obtain a truthful description of the experience, from the perspective of the experiencer.

Giorgi (2010, 18) argues that "*no claim for phenomenological status can be made if some legitimate type of reduction is not used*", stating that, unless the researcher practises rigid bracketing out of the natural attitude, using Husserl's reduction, research cannot claim to be phenomenological. I found Giorgi's criticism worrying; it made me question my phenomenological position and ultimately it was a viewpoint not easily accepted. De Voss (2012) articulates eloquently the difficulty philosophers and researchers alike have in accepting Husserl's reduction. De Voss (2012) muses that, like Frodo in the Lord of the Rings, at the end of his great adventure, he is unable to return to the shire and to his previous simple life-world; he claims that the same dynamic is at play for us all. An experience cannot be undone, and the effect of that experience cannot be removed from who we are, after it. Once in a psychology class, there is no way back, one's view of life prior to such induction is "*fore-closed*" (De Voss, 2012, 333). However, according to De Voss (2012, 334), the main argument is "*not that the modern subject has lost his or her naïve direct experience of the life-world. Rather, the modern subject is characterized by the endeavour to re-find the naïve experience*". In this context, although my knowledge of SAP was extensive, I had no experience of its effects on another's life-world, particularly related to farming. This allowed me to experience it as a "phenomenon" for the first time, in a relatively naïve and open manner.

I recognised early in the study that I had to limit the effect certain clinical knowledge had upon the way I perceived participants. I found myself agreeing with Ashworth (1996; cited in Finlay, 2009, 12) when he argues that three presuppositions need to be set aside; these are: (i) scientific theories, knowledge and explanation; (ii) truth or falsity of claims being made by participants; and (iii) personal views and

experiences of researchers which would cloud descriptions of the phenomenon itself.

I found the last point difficult to accept; however, during the early stages of analysis, the first two points helped me keep an open attitude, limiting the danger of “*naval gazing*” – i.e. privileging myself over the participant (Finlay 2011, 13).

Dahlberg et al. (2008, 98) argue that an open attitude is more than an aspect of method; it is “*an expression of a way of being*”, a willingness to listen actively and remain curious, without imposing pre-conceived viewpoints. Dahlberg et al. (2008, 112) argue that this principle is pivotal to both phenomenological and hermeneutic traditions, stating that openness “*means entering the world of a person and leaving behind any structure that would shape one’s expectations for what will be found*”. Thus, openness means being flexible in research approach, rather than following strict, predetermined procedures. However, it is also about a degree of objectivity in which the inter-subjective elements of the researcher and informant encounter are recognised, whereby openness remains directed towards the phenomenon being discussed and the informant. Dahlberg offers a technique, namely “*bridling*” as a practical enacting of openness, which I feel counters some of the methodological difficulties approaching participants from a hermeneutic phenomenological perspective.

5.7.3 Bridling

Snelgrove (2014) argues that qualitative researchers undertaking longitudinal research need to be wary of emotional involvement with subjects which may distort findings and advise buffering this by utilising reflexivity and the hermeneutic circle in their analysis of the data. From a hermeneutic phenomenological perspective it was important to acknowledge that I *would* be changed after every interview and look to be open about this within my own study. However, my use of “*bridling*” to delay early conceptualisations during analysis, as well as engaging

in the hermeneutic turn, did prove beneficial by maintaining my openness to the data.

Dahlberg et al. (2008) describe bridling as a restraining of one's own pre-understandings, so that a phenomenon is allowed to reveal itself. *"It is impossible to bracket all pre-understanding there is in the lifeworld, in the flesh of the world, but it is possible to 'bridle' the event of understanding"* (Dahlberg et al., 2008, 133). It is about not jumping to conclusions too soon, imposing one's theories too quickly. By doing so and reflecting upon, recognising the implications, the authors contend that it is the only way a researcher can see *"the 'otherness' of a phenomenon in the process of research"* (Dahlberg et al., 2008, 140). I recognised the worth and need to practise bridling during the early stages of my data gathering and analysis, in order to get as close as possible to the lived experiences of participants.

5.7.4 Lifeworld existentials

Common to all phenomenological study is the representation to some degree of the participant's lifeworld, as first postulated by Husserl and developed by other thinkers and writers since. In my struggle to represent participants accurately, while also wrestling with a large corpus of data, it was towards this base existential framework that I turned.

Smythe et al. (2008, 1392) argue that when working with and interpreting data, the researcher must avoid reducing, categorising the data to *"a set of surface qualities"*. They state: *"to remove a story from its rich textual background is to remove meaning and thus the possibility of understanding the experience as it is lived, for we can only ever live in a context of time, place and situational influences"*. The authors are not against *"themeing"* data, but suggest that a theme should not be viewed as stripped- down data, rather a signpost towards a specific discussion and further thinking by the author. When analysing the data, I was conscious of my own data and not *"stripping it*

down” into neat generalisations, just to make it more manageable. Although I would not be able to report everything I found, I still felt it important to maintain the continuity of participants’ stories.

Van Manen (1990, 78-79) warns against a mechanical approach to thematic analysis, in which counting and coding of selective terms takes precedence over an embodied “*seeing*” of meaning. Van Manen (1990, 90) states that “*phenomenological themes are not objects or generalisations: metaphorically speaking they are more like knots in the web of our experiences, around which certain lived experiences are spun and thus lived through as meaningful whole*”. He guides us to four fundamental lifeworld themes which “*probably pervade the lifeworlds of all human beings, regardless of their historical, cultural or social situatedness*” (Van Manen, 1990, 101). He suggests that these four aspects of human lived experience, termed “*existentials*” can act as a template for reflection within the research process, allowing us to “*perceive an immediate immense richness of meaning*” (Van Manen, 1990, 105). These four fundamental existentials are corporeality (lived body), spatiality (lived space), temporality (lived time) and relationality (lived relations with others), as described. Specifically:

- Lived Body (corporeality) refers to the phenomenological fact that we are always bodily in the world (Van Manen, 1990, 103). It is the lived qualities of human embodiment – movement, balance, the way our five senses take in the world and how we make perceptions about our lived space and interactions through them.
- Lived Space (spatiality) is felt space (Van Manen, 1990, 102). It is the way that people experience and know the environments and places in which they find themselves.
- Lived Time (temporality) is subjective time, as opposed to clock time or objective time (Van Manen, 1990, 104).
- Lived Other (relationality) is the lived relation we maintain with others in the interpersonal space that we share with them (Van Manen, 1990, 104).

Van Manen (1990, 105) highlights that the above can be differentiated, but never separated: “... *they all form an intricate unity which we call the lifeworld – our lived world*”. In this regard, a research study may wish to focus on spatiality, specifically; however, it must acknowledge that the other existential quarters will always be drawn under their lens, to some degree, in order to fully understand, in this example, spatiality.

The division of “*lived-world*” into separate yet interconnected elements is something that other researchers have used to provide insight into their subjects' lifeworlds. Ashworth (2003) argues that researchers should not consider the discovery of particular themes a prerequisite and conclusive stance, but should look at the existentials, to guide an open approach to their subjects' worlds. Finlay (2011, 234) also acknowledges that the use of such a pre-set framework can be a useful means of interrogating data and structure analysis.

Rich et al. (2013, 499) contend that the application of Van Manen's lifeworld existentials offers the researcher “*a holistic and valuable method for reflective practice, in coming to understand lived experience*”, as well as “*a lens through which to explore and navigate disparate interview data and uncover the essences of lived experience without imposing categories upon the data*”. I also agree with Rich et al. (2013, 508) in their reflection that the use of existentials offers “*a counter balance to data immersion*”, supporting them in “*stepping back from the data*”, so that they could “*consider the wider and more subtle aspects of the lived experience*” under investigation. I decided that the categorisation of data into these four existentials would help maintain “*the whole*” of the participants' experiences, while allowing me some bridled objectivity.

5.8 Writing Style

Phenomenologists disagree about the weight which should be accorded to scientific versus artistic elements in phenomenological research. Regarding the latter, descriptive phenomenologist

Applebaum (2010, 56) writes: *“If qualitative psychological researchers seek refuge in the arts and a postmodern equating of research with fiction, they invite the charge of subjectivism and the further marginalisation of qualitative approaches as literary and hence irrelevant to science”*.

Finlay (2009, 14) argues more diplomatically that *“researchers need to attend to the audience they are attempting to communicate with”*, shaping one’s style of reporting so that it has optimum relevance and impact. Sometimes, results are best presented highlighting the systematic, scientific nature of a study, whilst at other times a more creative re-presentation might prove more effective. However, according to Van Manen (1997, 345) the: *“formative power of phenomenological texts lies in this resonance that the word can effect”*, advocating that alongside the thematic aspects of social science research, stronger expressive writing should be encouraged. Van Manen (1990, 30) encourages the hermeneutic phenomenological researcher to *“describe the phenomenon through the art of writing and rewriting”*; for Van Manen phenomenology is the application of language and thoughtfulness to a phenomenon, allowing it to show itself as its *“self”* through our interpretation of it.

Gilgun (2005, 260) also argues against writing *“in distanced, third-person voices”* that silence participants and the researcher, in order to present *“vague, general statements”*, reasoning that such a writing style is seen as scientific, whereas *“lively, first-person writing is not”*. Gilgun (2005, 259) supports the use of the first-person in qualitative research, quoting from the American Psychological Association guidelines (APA, 2001, 38; cited in Gilgun 2005) which suggest that authors who do otherwise *“may give the impression that you did not take part in your own study”*. She encourages the researcher to write in such a way that it *“grabs”* the reader’s attention through its interesting and memorable style, without foregoing methodology. I found this a powerful paper and adopted it as a mantra for my subsequent approach to data reporting and writing style. Nevertheless, my decision to write in the first-person

and undertake a more creative reporting style proved difficult; going against my previous empirical viewpoint and ideas about what research, particularly within the healthcare arena, should look like. However, I felt I owed it to my participants to portray their experiences with the same degree of human connectivity for the reader.

5.9 Summary of the Chapter

This chapter aimed to describe the methodology bridging my research paradigm and philosophical platform, with methods chosen to conduct the Farm Angina Project. Within this chapter, I have highlighted some of the contentious issues regarding longitudinal hermeneutic phenomenological research, particularly related to phenomenological reduction, and my decision to use bridling (Dahlberg et al., 2008) as an appropriate and congruent alternative.

My decisions for undertaking embodied enquiry are also discussed, in relation to participant approach, type of data gathered and during analytic reflection. Finally, I have outlined my reasons for choosing a first-person writing style which encompasses both a scientific viewpoint, as well as a more creative representation of the findings, thus appealing to both “the head and the heart” of the reader, in line with hermeneutic phenomenology.

The next chapter builds upon this chapter and the previous chapter, to detail my methods for conducting the Farm Angina Project.

Chapter Six: Methods

“sat in limboland
just my heart complaint and me
the ward prisoner”



“...my biggest frustration was when I got...you got, I got moved up to the...admissions ward, and I was back in limbo land...I spent five days there...just on admissions, because nobody knew where they were going to put me...one says, no you haven’t had heart attack, another says oh yeah you have...”

Colin

6. Chapter Six: Method

6.1 Introduction

This chapter describes the methods used to undertake the Farm Angina Project, a longitudinal hermeneutic phenomenological research study, and my reasons for employing them. I shall also reflect the methodological and philosophical theory which underpins the study, thus ensuring that the research paradigm remains congruent.

Regarding hermeneutic phenomenology, Finlay (2011, 115) states: *“there is no actual method of how to do hermeneutic phenomenology”*, which she suggests can be limiting or liberating for new researchers. Smythe et al. (2008, 1392) also warn against *“the temptation ... to accept the philosophical underpinnings of methodology and then move swiftly into a neat, pre-ordained orderly method”*. From a hermeneutic phenomenological perspective, Smythe et al. (2008, 1392) remind us that one must consider the teachings of Heidegger and his Dasein – the researcher as *“being-there, being open, being in play, going with what comes, awaiting the moment of understanding”*. Hermeneutic phenomenology does not provide all the answers, rather it invites the reader to take a journey with the author, with sufficient freedom to think, interpret and make up their own mind (Smythe et al., 2008). However, there is criticism regarding the lack of philosophically formulated direction towards method within hermeneutic phenomenology (Giorgi, 2010; Applebaum, 2010). Giorgi (2010, 5) argues that *“some sense of theoretical justification of how a method is to be utilised is required, not a mere description of how it is done”*. According to Giorgi (2010), it is an imperative, scientific criterion that phenomenological researchers accurately report why and how method was employed. This is obviously a requirement for Ph.D. research, where the researcher must demonstrate their apprenticeship in the craft, as it were. In some ways, this makes my choice of a hermeneutic phenomenological approach

challenging, recognising the need to appeal to “*the head and the heart*” of the reader, with just the right artistic and academic balance.

I shall now describe, in detail, the methods utilised to obtain the data required to answer my research question, and offer reasons for my decisions, in each section.

6.2 Sample Selection and Recruitment

Steeves (2000, 46) suggests that, from a hermeneutic phenomenological perspective, it is useful to consider the phenomenon of interest from three possible individual sampling frames: “*the experience of place, the experience of events in time, and ways of talking about the experience*”. I felt that I could not answer the study question, if I utilised only one of these perspectives to formulate sample inclusion criteria, as SAP would affect all three, at the same time. Instead, homogeneity was linked to Van Manen’s (1990) four existentials:

- lived bodily perception, in this case, angina as suffered or observed;
- lived place, in this case, life on a farm, as well as visits to the hospital;
- lived time, following participants through the same farming year and treatment regimen; and
- lived other, in this case, close partner and medical staff.

My sample needed to represent commonalities within each of these existentials because, in my opinion, these were necessary to capture the lived experiences of SAP in farming dyads, from a whole lifeworld perspective.

Time and place based purposive, homogenous sampling was therefore employed to recruit patients on to the study, who had experienced the phenomenon under investigation, i.e. farmers (and / or their partners), who are seen in the Rapid Access Chest Pain Clinic (RACPC) or Angiography Suite at Hereford County Hospital (HCH) and who are

subsequently diagnosed as suffering from SAP. The following inclusion criteria (see Table 2) helped guide this process:

Table 2: The Farm Angina Project Inclusion Criteria:

	Inclusion Criteria:	Reasoning:
1	Newly diagnosed with stable angina pectoris of cardiac origin (symptoms of less than 6 months duration). Inclusive of those awaiting formal diagnosis after investigation for SAP.	The study is looking to capture initial experiences and perceptions of people from farming communities, newly diagnosed with angina pectoris of cardiac origin.
2	A member of a farming dyad, either as the person with primary farming responsibilities, joint farming responsibilities or the partner of either of the above.	The primary aim of the research is to explore the experiences of farming dyads in which one of the couple has newly diagnosed angina pectoris.
3	Married or in a partnership of > 2 Years' duration.	The study wishes to engage with couples who have lived together and have a history of joint experiences.
4	Resides / receives cardiology treatment in Herefordshire.	Ethical approval will only be sought from Herefordshire Research & Development Committee.
5	Willing to provide written informed consent prior to study entry.	Written informed consent is required to undertake this research.
6	Able to speak and read English.	The research will be undertaken in the English language only and likewise all printed matter.

The inclusion criteria were designed to capture a cohort of participants from a Herefordshire farming background. This acknowledgment of the culture and environment, as applicable to the experiences under investigation, is in keeping with more contemporary interpretive phenomenology, but in contrast to descriptive phenomenology, where culture and inherited understandings are set aside, in order to see the phenomenon as it really is (Caelli, 2000, 371).

Starks and Brown Trinidad (2007) suggest that typical sample sizes for phenomenological studies range from one to ten. Smith et al. (2009, 52) offer that between four and ten IPA interviews is a good guide for professional doctorates, warning against seeing higher numbers as being indicative of better work. Morse (2000) also states that study design should take into consideration the amount of data the researcher hopes to gain from each participant and advises that longitudinal studies in which other members of the family are included produces more data than single interview per participant design. The author suggests that, if one is conducting a phenomenological study and interviewing each person, many times, one has a large amount of data for each participant and therefore needs fewer participants in the study (perhaps only six to ten).

Bearing these perspectives in mind and other factors such as drop-out, particularly with respect to both partners completing, the study hoped to recruit ten dyads, in the first instance. It was envisaged that four to six dyads (eight to twelve participants) might complete the study, in line with the recommendations referred to and reflecting the study's intention to demonstrate a bold design (Smith et al., 2009). Saldana (2003) argues that researchers should have an Attrition Contingency Plan, so that research does not fail to recruit the amount required. He recommends that the research should "*start with more participants than you might actually need as a precautionary measure*" (Saldana, 2003, 21), particularly within longitudinal studies, where long-term commitment is required by participants. It was feared that recruitment might be difficult for a number of reasons, such as a limited number of

potential candidates coming through Cardiology, and reluctance to participate from those who were approached, due to competing work commitments, or ill health. It was also envisaged that, once recruited on to the study, attrition rates would be potentially high, again due to the nature and seasonality of farming, making attendance at interviews difficult, during busy times of the year.

The Farm Angina Project was launched using information booklets (Appendix B) that were situated in patient waiting rooms and recovery areas within the RACPC and Angiography. All Herefordshire General Practitioners received letters explaining the aims and objectives of the study. It was deemed unnecessary to contact GPs for permission, every time a participant was recruited.

It was important to successful recruitment that clinical staff working in recruitment areas supported the study (Patel et al., 2003). To this end, senior nurses who worked in Rapid Cardiology and Angiography at HCH were invited to join a Steering Group which would help to co-ordinate the Farm Angina Project. They were trained to detect people who fulfilled the inclusion criteria and present the study to potential participants, along with the dissemination of supportive documentation. I also made myself available as much as possible, during clinics, where recruitment might be gained. It was important that those approaching potential clients were seen as clinically professional, with good interpersonal skills, including an ability *"to be respectful, tolerant, tactful and approachable and to show a caring and compassionate attitude"* (Patel et al., 2003, 234). They were tasked with presenting the objectives of the research to interested parties, alongside assurances regarding confidentiality. Primary SAP sufferers were usually approached first, unless a request for more information came from a partner.

It was recognised that, once approached, potential participants would conduct a personal cost-benefit analysis, when deciding whether to be involved, as any time away from their work would have some impact,

either in time, cost or inconvenience (Patel et al., 2003). Therefore, all potential participants were offered interviews where they worked or lived, at a time of day or evening that was most convenient, as well as financial compensation for their time during interview.

The study adopted a Reimbursement Model, in that there should be no financial sacrifice by the research participant. This, I considered to be a particularly important factor with regards to farmers, who may have to come away from farm duties to attend for interview. Payment to participants was only for costs, e.g. travel expenses, child-care expenses, meals and demonstrable loss of earnings, up to a maximum of £10 per hour. Participants were advised that they should not be required to actively input the study over five hours in total, over the twelve-month period.

Over a five-month period, ten dyads were recruited to the Farm Angina Project. Eight dyads completed the study. This also confirms that the recruitment protocol observed was appropriate for this particular cohort. However, eight couples equates to 48 interviews, which had important consequences for how the data could be analysed and to which I will return.

Recruitment started in October 2010 and initial first-stage interviews began in January 2011 and finished in April 2011. Participants were recruited from all across the county of Herefordshire. Second-stage interviews took place between June and October, 2011. Third-stage interviews took place between November 2011 and April 2012. All the SAP sufferers recruited were male and held primary farming responsibilities, which meant the opportunity to investigate female SAP sufferers' experiences was not realised. Participant details were as in Table 3 (male) and Table 4 (female):

Age:	Job:	Angina history at 1st interview:
48	Farm Manager Stock/Arable	Chest pain 6 months, awaiting diagnosis
51	Fruit Farmer	PCI Nov 2010, SAP 2 mths.
60	Organic/Sheep Farmer	SAP, PCI Stents Nov 2010
84	Sheep/Arable Farmer	SAP, PCI Stents Oct 2010
60	Poultry Cons/Goat/Bees	SAP, CABG Jan 2011
61	Dairyman	Chest pain 6 months, SAP 4 months
70	Sheep/Arable Farmer	SAP, PCI Stents Dec 2010
69	Sheep/Arable Farmer	SAP, CABG Jan 2011
51	Ploughman	Chest pain 6 months, SAP 2 months
65	Bee-Keeper/Sheep	Chest pain 2 months, awaiting diagnosis

Table 3: Male Participant Details

Age:	Job:	Partners work role:
46	Care Home Manager	Farm Manager
50	School Teacher	Fruit Farmer
64	Organic/Sheep Farmer	Organic/Sheep Farmer/Vet
79	Costume Designer	Sheep/Arable Farmer
60	Counsellor/OT	Poultry Consultant/Goat/Bee- Keeper
69	Sheep/Arable Farmer	Sheep/Arable Farmer
40	Housewife	Ploughman
59	Teacher/Charity work	Bee-Keeper/Sheep
46	Housewife	Dairyman
72	Sheep/Arable Farmer	Sheep/Arable Farmer

Table 4: Female Participant Details

The field-work was guided and monitored by a steering group who met quarterly during data collection and the analysis process, these individuals are listed in Table 5:

Name:	Title:
Stephen Heptinstall	Chief Researcher
James Glancy	Consultant Cardiologist HCH
Neeraj Prasad	Consultant Cardiologist HCH
Paula Smith	Primary Supervisor UOB
Helen Lucey	Second Supervisor UOB
Anne Marie Scott	Cardiac Rehabilitation CNS HCH
Patricia East	Cardiac Rehabilitation Lead Nurse HCH
Trisha Meredith	Specialist Services Manager HPCT
Lyle Howls	Service Improvement Officer, Cardiac Network
Caroline Gwynne	Cardiology CNS HCH
Kate Duffett	Cardiology CNS HCH
Susanna Hicks	Sister, Day Case HCH
Iain Watt	GP/Patient Representative
Phillip Cleland	GP/Patient Representative
Claire Pritchard	Partner of Farmer

Table 5: Farm Angina Project Fieldwork Steering Group

6.3 Data Collection

Data collection comprised two parts: semi-structured interviews and reflexive notes made by the researcher.

6.3.1 Interview approach

The interview approach chosen was one that followed hermeneutical principles; interactions were open, conversational and questions asked only when required. Koch (1996) states that openness is critical and the exchange may be entirely open, with few direct questions asked. The author argues this encourages the interview process to stay as close to the lived experience as possible. I reflected that I would find such open interviewing difficult as, in my healthcare role, I am used to directing interactions with patients through specific questioning. However, this was also a challenge to my prejudices that I could not ignore.

Van Manen (1990, 66) states that, in hermeneutic phenomenology, the interview not only serves to gather experiential narrative material, but

also provides a way of building up a relationship with the interviewee. The researcher should strive in their intention to balance both, so that a sensitive and rich understanding of the phenomena under investigation can grow. He argues that this can be achieved through a conversational style of interviewing that remains disciplined by the fundamental question that prompted the interview, in the first place. He warns against an “*open-ended and unstructured*” interview style, in which the researcher ends up “*going everywhere and nowhere*” (Van Manen, 1990, 67) and is left with reams of unmanageable data. However, Steeves (2000, 62) argues that researchers should allow informants some freedom to discuss what is important to them, and not through fear of irrelevance, direct the conversation too firmly: “*If a topic is not of enough interest to the informants to be included in their narratives, however, it probably is not an important part of their experience and not worthy of the researcher’s pursuit*”. Finally, Smythe et al. (2008) warn against researchers entering into a mindset of “*conducting*” a formal interview, arguing that this rigid approach freezes the phenomenological spirit. Rather, they suggest an “openness” that allows the researcher to enter into discussion with participants, and allows what is important to their experiences to come forth. In the end, open, semi-structured interviews were used to collect data from participants, using a schedule to support the process, as advised by Smith et al. (2009) but not to lead it. It was important to show that interviews had structure and purpose, not least to gain ethical approval. However, I also recognised the need to be flexible and open in my approach to allow participants not to be coerced into a certain type of recollection, because of my clinical position.

Some consideration of joint interviewing over individual interviews was made. Morris (2001) warns that attempting to undertake separate interviews with couples can be problematic, and raises ethical concerns, arguing that the act of conducting separate interviews may stir up antagonisms, as it suggests that each couple would speak more truthfully without the other. Arksey (1996), however, references a

number of papers which suggest there are inherent disadvantages to the joint interview approach, related to dominance by one of the participants and the potential for stirring up antagonisms and conflicts of interest *during* the meeting. Amarapurkar and Danes (2005, 427) undertook a study of 206 farm-business owning couples, to understand relational tensions within these dyads. They found that “*it is critical to perform a separate analyses for husbands and wives for a fundamental understanding of the individual*”, as each person perceives relational tensions in different ways. Bearing these perspectives in mind and recognising that the aim of the project (to gain an understanding of each person’s experiences of SAP, from the sufferer and partner’s perspective), I decided to interview participants separately and, with hindsight, I am glad that I did. I found interviews were more candid and revealing about the benefits, but also difficulties, that dyads faced when dealing with illness in a farming setting.

6.3.2 Questions

Taped, semi-structured interviews were used to gather verbal data. These were undertaken individually, with the primary SAP sufferer and their partner, in their own homes. Three interviews were undertaken with each participant, separated by two six-monthly intervals, over a twelve-month period. I organised the interviews this way, in order to capture data related to the longitudinal progression of the condition. It is argued that a longitudinal approach recognises that more personal accounts are likely to be elicited through multiple interviews and that it also allows the researcher to revisit issues raised previously (Whitehead, 2004). Smith et al. (2009, 52) also suggest that a longitudinal study such as this can help to produce “*a more detailed and multi-faceted account of the phenomenon*”, due to length of time it is studied.

Smith et al. (2009) suggest that six to ten open questions will occupy between 45-90 minutes of conversation. A schedule of ten questions

over one hour was therefore planned for each interview (see Appendix E). The aim was to complete each set of two interviews, in one sitting. Interviews were iterative, to allow individual stories to be followed up, in more detail, and the schedule and process did change, over time, to reflect the individual nature of each interview and explore specific information, in greater detail.

Gadamer (1975/2004, 363) states: *“we can understand the text only when we have understood the question to which it is an answer”*. Consideration over the direction of questions, how many, the requirements of ethics to demonstrate responsibility, all influenced the final choices made. The interview was structured to allow openness. It was both prospective and retrospective in its view, recognising the need to capture a sense of the individual informant’s temporality, what had been, what was still to come, and how both affected the present.

The interview schedule was divided into a review of their farming life and followed by their illness experiences. The idea behind this was to allow informants to discuss, generally, their lives, before moving on to what might be perceived as more difficult questions to answer. As Steeves (2000, 47) states: *“For the hermeneutic phenomenological researcher, it is useful to look at places and how the experience of place is a part of the phenomenon in which we are interested”*. Certainly, I expected that the farm and physical work required would be integral to the SAP sufferer’s experience of their angina and, therefore, questions related to this were necessary. I also wanted to gain some insight into the wider social and cultural influences on participants. Addison (1989) also argues that if one takes participants experiences of a phenomenon, without reference to the wider context of their lives, this leaves the researcher disadvantaged in their interpretation.

Second- and third-stage interviews followed a similar line of questioning; although individual stories led to differing lines of enquiry, at these subsequent times (see Appendix E).

6.3.3 Use of Tape Recorder

Consideration was given regarding whether interviews should be taped. As Steeves (2000, 32-33) warns, the very presence of the tape-recorder might be “*intrusive enough to change the quality of the data*”. However, I could not perceive of another way to gather data succinctly and any less obviously, such as note-taking, which would have affected discourse even more in my opinion, other than completely relying on reflection. In order to obtain an accurate representation of participants’ experiences, I decided that a tape recorder would have to be used. In reality, I found that most participants appeared to forget it was there, even when it was the only object sitting on the table between us.

6.3.4 Reflexivity

Qualitative research and the process of analysis involve continuous reflexivity and self-scrutiny. Reflexivity can be defined as thoughtful, conscious self-awareness (Finlay, 2002). The theoretical concept of reflexivity depends on a person’s particular point of view. Phenomenologists focus on the way subject and object are enmeshed in pre-reflective existence. In Gadamerian terms, reflexivity involves a positive evaluation of the researcher’s own experiences, to help him understand the fusion of horizons between subjects and their surroundings (Finlay, 2002). Finlay (2002) advises that the phenomenological researcher starts their project with the data of their own experiences; their own reflecting, intuiting, and thinking as primary evidence. At a minimum, then, reflexivity is an acknowledgement of researcher bias; however, for this study, it adopts a more active level, embracing subjectivity and the researcher’s insights (as a Cardiac Rehabilitation Practitioner) to be important contributions to the research.

Field-notes are recognised as a secondary data gathering and storage method in qualitative research, particularly in this type of study. Although, there are many ways of undertaking this process, I decided to

log my subjective experiencing, before I could conceptualise it and reflect my embodied experiences of the data gathering process.

Field-notes included my “*subjective experiencing*” related to certain “gut” feelings, change in mood, sudden thoughts disconnected from any particular order or process. Gendlin (1962/1997, 228/230) describes subjective experiencing as a dimension that each one of us knows intimately; it is “*an individual’s feeling of having experience. It is a continuous stream of feelings with some few explicit contents*” and is prior to any conceptualisation. Gendlin (1962/1997, 228) argues against more positivistic research trends, in that utilising subjective experiencing is an important aspect of researching everyday phenomena, where “*neither construct nor external observations quite succeed in replacing subjective experiencing*”. These notes took the form of scribbles, poetic lines, verbal recordings made sitting in lay-bys, on the way to and from interviews and sometimes photographs, snapped during my travels. My field-notes became more important as my study progressed. To begin with I was not convinced they were a good use of my time, however during analysis their true worth emerged, offering depth to the recorded narratives, and allowing me to recall more accurately my embodied experiences during meetings.

Drawing on the work of Merleau-Ponty, Finlay (2006) also identifies three aspects of embodiment reflection I also incorporated within my reflective diary, these were (i) bodily empathy – involves the researcher paying attention to the participant’s general observable body language and demeanour; (ii) embodied self-awareness – involves the researcher noting their own body responses during their visit and interactions with participants, their “*gut feelings / reactions*”; (iii) Embodied inter-subjectivity – Finlay (2006) describes this as the “*in-between*” that occurs between the researcher and the researched – the “*more*” of the lifeworld.

6.4 Ethical Considerations

Ethical approval was gained on the following dates:

- June 2010 - The University of Bath agreed to act as a sponsor for this research.
- November 2010 – Study formally approved by The Black Country NHS Ethics Committee, with permission given to undertake research at Hereford County Hospital.

6.4.1 Expected ethical issues

The research protocol acknowledged two possible ethical issues from individuals' participation in the study. Reflecting the impact SAP has on them may prompt participants to assess for themselves that they require additional support. Preparation of a Support Sheet was developed, which could be passed to participants at the researcher's discretion (Appendix C). A named Cardiac Clinical Nurse Specialist agreed to be a contact for participants who wished to discuss support issues. Whitehead (2004) discusses her difficulty (as a nurse) maintaining a non-therapeutic relationship and resisting the temptation to intervene or influence the care being received by her participants, during interview. Within this study, I too was aware of this possibility (as a Cardiac Rehabilitation Practitioner) in responses to participants' issues; and needed to consider restraint, without losing a sense of useful reciprocity.

The second ethical concern related to interviewing dyads, separately. Interviewing couples separately can be problematic and may cause issues related to what is or is not disclosed to the researcher and to each other (Morris, 2001). The main ethical concern related to the planning of this study was whether to use individual or joint interviewing, as discussed earlier.

6.4.2 The unexpected

Two female partners left their husbands, mid-way through the study, although one later returned. I found this a daunting and uncomfortable dilemma. My decision to continue to interview them both was fraught with uncertainty. Although I continued to visit the farmer on his farm, I interviewed his now ex-partner at the hospital. I was aware that each “fished” for information about the other, during interview; therefore, I had to be very careful not to reveal anything deemed confidential about their partner. Saldana (2003, 29) warns: *“despite how much is learned or disclosed to you over a long-term fieldwork period, you will never know everything about your participants and must be careful about assuming you do”*. This struck a chord with me; I had not seen the separation coming from the information shared or any embodied experiences I had noted at first interview with these couples; only that they were struggling with illness more noticeably than some of the other couples.

6.4.3 Lone worker danger

I would be visiting couples I knew little about on farms within the remotest areas of Herefordshire and so safety measures were put in place to limit any harm to me during data collection. Inherent to such activity was the risk of getting lost, communication difficulties and dangers linked to a farm, (e.g. heavy machinery and animals). I made myself aware of and adhered to Herefordshire Primary Care Trusts Lone Worker Policy. A system of communication was also put in place to ensure a nominated person within the Cardiac Rehabilitation Department logged me out and in again, knew of my destination and approximate time spent there. If they had not heard from me within the allotted time frame, then this person was to try to contact me; failing this, the venue directly. If they were still unable to make contact, then they were to notify the police. To limit any such occurrence I carried a mobile phone and used satellite navigation to aid my journeys. In

reality the only “*danger*” I faced during the field-work was an over-enthusiastic collie dog that jumped up to say hello, covering me in mud.

6.4.4 Confidentiality

The NHS Code of Confidentiality was followed to ensure the confidentiality of personal data. To help protect anonymity, each participant was assigned a multi-digit, unique identifier, which was used on all associated research documentation, including interview recordings, transcripts and field-notes. This label was converted in to a pseudonym for the purposes of the thesis. Even here, pseudonyms were checked against all participants’ real names, to ensure that no names were duplicated. Partners were given different first and second level pseudonyms, to protect inter-relational confidentiality. Any names, places, or other possibly identifiable information shared at interview were also anonymised, before publication, other than details related to role, i.e. primary farmer, farm-worker or partner of either.

Only I had access to participants’ medical records and personal data, prior to recruitment. Personal data were shared with the study’s academic supervisors from the University of Bath, after recruitment. Participants were informed through an information sheet, consent form and verbally by me as the chief researcher who may have access to their study data, and why.

All electronic data were stored in Hereford Hospital NHS Trust’s computer mainframe, with code protected access available to only me as the chief researcher. An encrypted laptop was used to enter data, including demographic and other participant details, audio files and transcription data.

Paper data were stored in a locked filing cabinet, located in the CR office at HCH. This office is locked when unoccupied. The building in which this office is sited is also locked at night and at weekends. Only I had access to data, unless I should leave the service. Should this

happen, the CR Manager would then take over responsibility for the safe storage and ultimate safe destruction of this material.

How I was going to report on the data proved problematic, from a confidentiality perspective. I was aware of issues in other community studies where pseudonyms had been used; nevertheless, participants were clearly recognisable to each other through their reported social positions (as in Vidich and Bensman's, [2000] treatment of the people of Springdale in their book, *"Small Town in a Mass Society"*). I considered using composite narratives to outline my findings, but eventually concluded that only brief quotations should be used, avoiding any references to details easily recognisable to the other partner.

There is a tradition of giving communities pseudonyms (Crow and Maclean, 2000); however, I did not think this was warranted in this study. Indeed, I want the reader to be able to identify with the area, to some extent, both its history and landscape, so that a sense of perspective is possible. It can be argued that some places are so recognisable that no attempt is worth making, such as Phals's (1984) study of the Isle of Sheppey, for instance. Any identifiers related to the farms, homes and local area landmarks of participants were anonymised, using pseudonyms; however, the main towns and county name were not. Towards the end of the study, I also decided to use photographs of the old and new farmers' market in Hereford, to frame a series of poetry based on my data. In accordance with Crow and Wiles (2008), the rationale for including photographs is to give a stronger sense of the type of place participants might frequent and the community under review; by using images not directly linked to any individual participant, there appeared no issue for me, here.

6.4.5 Trustworthiness and rigour

In hermeneutic phenomenological research, issues of rigour are addressed by demonstrating clearly the multiple stages of interpretation

that allow patterns to emerge and the discussion of how interpretations arise from the data (Koch, 1996). Guba and Lincoln (1981) offer a four-point strategy to maintain validity and rigour, which guided my decisions and presentation of the study:

- Credibility – trustworthiness can be endorsed, if the researcher is transparent about their experiences and interpretation of them (Whitehead, 2004).
- Dependability – the study is transferable because the researcher provides a decision trail throughout and avoids ambiguity.
- Confirmability – the researcher shows how decisions and interpretations are arrived at, throughout the inquiry.
- Trustworthiness – attention to reflexivity and how historicity affects the whole process of inquiry are included.

Conroy (2003) suggests that logs maintain the spirit of the researcher-as-reflector, during the entire process, recommending three divisions of reflection which I utilised to inform the Steering Group about my progress. This included an “Ongoing Log” – providing an account of the research process, including evidence of contacts with other agencies, other than participants, timetabling and one’s own perceptions of these factors. Secondly a Decision Trail – detailing how and why decisions were made, with supporting evidence. Finally a Reflective Diary – noting subjective and embodied experiencing, as outlined earlier.

The qualitative data collected were also subject to independent analysis by the study supervisors. The findings were presented to the steering group, at regular intervals. These procedures ensured that the conduct of the study was regularly monitored and any unexpected problems, for example, in recruitment, could be identified and dealt with, at an early stage.

6.5 Analysis

Analysis was in three stages. Most of my Stage One analysis was undertaken, as data were collected. In this way, I gained an understanding of participants' experiences, as we moved through the twelve-months of the study. Stage Two data analysis was undertaken after completion of each round of interviews. Stage Three analysis was only possible, once all the data had been collected, at the end of the fieldwork period. These stages are summarised diagrammatically, below, with a detailed description to follow:

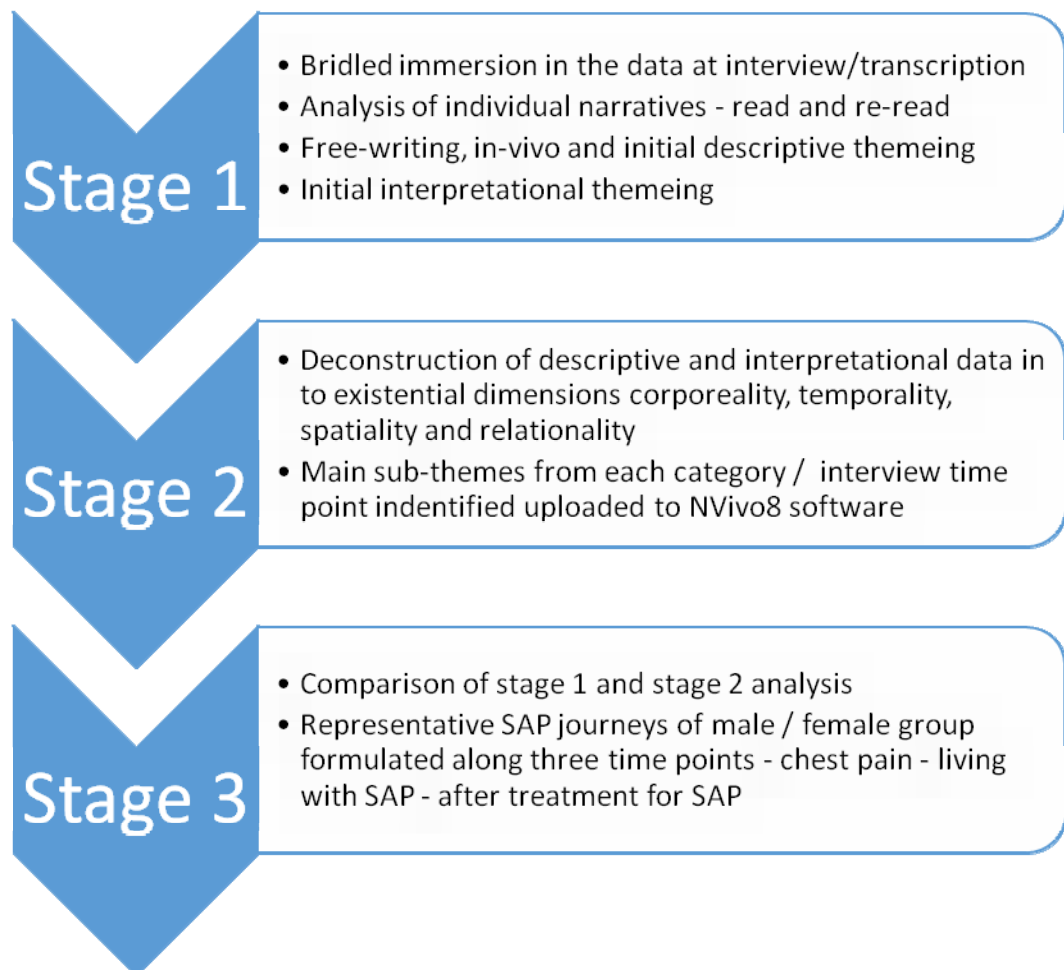


Figure B. A diagrammatic representation of the three stages of analysis undertaken in the Farm Angina Project.

Maggs-Rapport (2001) suggests that the relationship between sample development, size and data analysis technique is often overlooked, but is an important aspect of a methodologically congruent study. Certainly, with 48 interviews I had a large amount of data, which made me question whether I could, indeed, utilise a hermeneutic phenomenological approach to analyse this, confidently and in good time. After some debate, I undertook a three-stage analysis approach, which took in to consideration the sizeable corpus of data obtained, alongside the need to remain congruent with my methodology.

6.5.1 Stage one: Bridled immersion

An open and bridled approach was applied to the data, during this stage of analysis. Bridling maintains a hold on the researcher, so that they do not attempt to understand prematurely, *“that they do not make definite what is indefinite”* (Dahlberg et al., 2008, 130); in other words, actively waiting to perceive meaning from data, so that the phenomenon has time to show itself. Certainly, during stage one analysis, I found the application of early interpretation of text limited my findings to reflections of my own pre-understandings. This is why I adopted *“bridling”* as advocated in a reflective lifeworld research approach, even though my approach was not from a Husserlian perspective.

A “selective” and “detailed line-by-line” approach were used at this stage, to help locate emerging themes within each individual narrative. These involve the following:

- The selective approach – here the researcher listens or reads the text several times and asks: *“what statements or phrases seem particularly essential or revealing about the phenomenon or experience being described?”* (Van Manen, 1990, 93). The researcher then highlights these statements within the text.
- The detailed or line-by-line approach – the researcher looks at every line of text or sentence cluster and asks: *“what does this sentence*

or sentence cluster reveal about the phenomenon or experience being described?" (Van Manen, 1990, 93).

I used columned paper narrative templates (Appendix F) to highlight descriptive sub-themes, alongside my own reflective journaling and free writing thoughts made during this analysis.

As Dahlberg et al. (2008, 243) state: *"when the data are familiar as a whole, the character of reading changes; the different parts begin to emerge"*. I was wary, at this point, that my eventual sample size and amount of data gained would ultimately have influence over how I could interrogate data. The Reflective Lifeworld Research advocated by Dahlberg et al. (2008) and to which, until now, I had been allied, begins to break down text into psychologically sensitive meaning units, as advocated by Giorgi (2009). However, my corpus of data meant that such an approach was untenable, due to time constraints. Importantly, it can also be argued that the use of Giorgi's descriptive method of phenomenology (Giorgi, 2009) within a hermeneutic phenomenological study is incorrect, because it is allied to Husserlian descriptive phenomenology and therefore differing methodology. That aside, I was left with a problem. Giorgi, (2010, 18) is critical of mixed qualitative method within research, stating that there *"is a logic to following a method and it cannot be assumed that the procedures of another method will follow the same logic as the initial one"*. I understood this reasoning and knew I needed to be careful as to how I next proceeded with my analysis. It was towards the work of Max Van Manen that I was able to move forwards, confident that congruence in my approach was maintained and I that could develop my analysis appropriately.

6.5.2 Stage two: Deconstruction of data

Van Manen (1990) guides us to the four fundamental lifeworld dimensions: corporeality (lived body), spatiality (lived space), temporality (lived time) and relationality (lived relations with others),

stating that these four aspects of human lived experience can act as a template for reflection within the research process, allowing us to “*perceive an immediate immense richness of meaning*” (Van Manen, 1990, 105). I decided that these four existentials would work well as knots around which I could begin to wind the experiences of participants.

During Stage Two, participant narratives were divided up into the four lifeworld existentials and assessed from that viewpoint. Interviews were imported in to NVivo8, a software package designed to store and analyse qualitative material (QSR International, 2008). This allowed me to manage the large corpus of data to hand and move between the whole and the specific, within it smoothly; thereby allowing me to enter in to a hermeneutic circle of understanding (see Appendix K). Nvivo8 was only used for data management and handling and not as a tool for directly interpreting the data. This is important to clarify, as the latter would have been contrary to the interpretive phenomenological ethos underpinning this study, that the lived and co-constructed experiences of the researcher during the analysis process are integral to the findings of such research.

At this stage use of numeration, taking into account the frequency with which a descriptive theme is supported was utilised. Smith et al. (2009, 98) warn against the researcher considering numeration a reflection of the importance of a particular theme, but suggest it may help a pattern to emerge, across cases. Smith et al. (2009, 106) argue that the consequences of a larger corpus may be that analysis cannot be so detailed. They also suggest shifting the emphasis of analysis towards the whole group and key emergent themes from it, while also retaining examples from individuals to help illustrate such findings. The authors argue that measuring recurrence across cases is important, although there are no rules as to what counts as recurrence. They suggest that the decision has to stay with the researcher, guided by the aims and limitations of the study.

Information which appeared important to individual participants was included; much of this was taken from impressions made during Stage One. Slowly, themes began to emerge within each existential category and along each of the three interview time-points. These themes were maintained within NVivo8 to assist in maintaining a clear overview. Van Manen (1990, 33) states that the researcher must “*balance the research context by considering parts and whole*”, i.e. one must continue to monitor the overall design of any study, so that it remains relevant and each part significant to the phenomenon under investigation. He argues that this requires the researcher to move, constantly, from the specific in their writing to the global, so that they do not lose sight of their aims. Van Manen (1990) concludes that the aim is to produce a text in which dialogical structure and argumentative organisation create a certain effect and ultimately a well-balanced phenomenological study.

The amalgamated quotations within each existential sub-category were analysed to uncover themes relevant to the participants’ shared experiences. Finally, themes across the three interview rounds were analysed and interpretation of participants’ progressive SAP experiences within each existential developed.

6.5.3 Stage three: Reconstructing the data

Saldana (2003, 62) states: “*there are no prescriptive, systematic, or universal formulas for analysing longitudinal qualitative data. Each study and its methodology are context-specific and rely on the creative artistry of the analyst to make sense of it all*”. Thompson and Holland (2003) discuss how they struggled to undertake analysis, ahead of data collection completion, in their nine-year longitudinal study. They concede that, with every new round of data collection, previous interpretations were rendered redundant. This absence of analytic closure proved frustrating and made them question how one can best account for the changing “*subject in process*”. Rather than fear this

“provisionality of interpretation” (Thompson and Holland, 2003, 243), I welcomed it. Acknowledgment that there would be change was the only reason for undertaking this type of research, in the first place. I wished to understand the journeys of experience farming dyads went on with SAP.

Saldana (2003, 64) offers four analytic questions to guide interpretive analysis of longitudinal qualitative data:

- Which changes interrelate through time?
- Which changes through time oppose or harmonize with natural human development or constructed social processes?
- What are participant or conceptual rhythms (phases, stages, cycles, and so on) through time?
- What is the through-line of the study?

Each of these questions was put to the data, and aided the formulation of a detailed interpretive analysis.

Eventually, a reconstituted interpretation of participants' longitudinal SAP experiences emerged, built upon analysis at Stages One and Two, within my hermeneutic phenomenological framework. Integral to this was my engagement with the hermeneutic circle, a metaphor for the movement which takes place between understanding and interpretation. This is often viewed as an oscillating process between two poles, from the detailed engagement with parts of one's data towards an evolving wholeness of understanding for the whole of the phenomenon under investigation; *“each giving meaning to the other such that understanding is circular and iterative”* (Ajjawi and Higgs, 2007, 623). In other words, understanding and interpretation were born out of the dialogue which took place between myself as the researcher and my study data. This also included re-presentations of the data, through the use of creative writing, as discussed at the end of chapter one. In assuming a hermeneutic phenomenological position of openness, I was also reminded that I cannot discover everything about

the subject of my gaze, that there is no absolute truth and what I understand is always in the process of change. The end product (if there is ever an end) was a journeyed interpretation of SAP experiences in farming dyads around three key temporal periods in the participants' years, these being: (i) developing chest pain; (ii) diagnosis of SAP; and (iii) successful alleviation of SAP symptoms.

6.6 Summary of the Chapter

The aim of this chapter is to give a detailed account of the methods chosen to gather and analyse data related to the Farm Angina Project, which were congruent with the study's hermeneutic phenomenological methodology and longitudinal approach. This chapter describes the practical considerations and issues related to the research and how I dealt with these, during the study period. In the next two chapters, I shall detail the journeyed interpretations of farming dyads' SAP experiences, based on my three-stage analysis.

Chapter Seven: FINDINGS

“you need a bypass
just “matter-of-fact” like that
the car park – we cry”



7. Chapter Seven: FINDINGS

“To love is to be lonely. Every love eventually is broken by illness, separation, or death. The exquisite nature of love, the unique quality or dimension is its highest peak, threatened by change and termination and by the fact that the loved one does not always feel or know or understand.”

- Moustakas (1961, page 101)

7.1 Reflection One: To Love is To Be Lonely

I found Moustakas's (1961) early text “Loneliness” in a second-hand bookshop in Hay-On-Wye, just outside Herefordshire. It was the middle of winter 2011 (one of the coldest on record) and the weather had driven me to take shelter. I was returning from a first-stage interview with a couple on a remote farm, clung to the English-Welsh border. As I flicked through the book over a coffee I came upon this paragraph and the words resonated with me. I realised I had sensed the loss and loneliness of which Moustakas wrote in a number of my participants, to-date, their stories seemingly distant and isolated from each other, despite sharing the same experiences to all intents and purposes. I was left bemused, questioning why these couples appeared to have fallen out of step with each other. As I got to know each of these individuals, their truths slowly unfolded before me and over the year of study I grew to understand a little better.

7.2 Introduction

My findings are divided into three sections, reflecting the important temporal periods in participants experiencing, made available through my longitudinal, hermeneutic phenomenological approach. I use a

Merleau-Pontian view of corporeality and intercorporeality to offer an embodied, narrative interpretation of participants' experiences of SAP, drawing attention to the individuality of SAP sufferer / partner journeys, during three time periods of illness. The first section focusses upon chest pain leading to a diagnosis of SAP; the second section concentrates on participants' experiences after diagnosis, and the introduction of medical treatment and the third section covers the successful alleviation of SAP symptoms for most of the sufferers or their accommodation to it.

7.3 Period One: “Body Made Visible”: The Lived Experiences of Farming Dyads with Chest Pain

This first section describes and discusses the period before a formal diagnosis of SAP was made, in which the men were experiencing chest pain and the women, for the most part, were kept unaware. This provides a powerful testimony to the unspoken language of intercorporeality and how lifeworlds became shaped by actions, before words, to a certain extent.

7.3.1 The male farmer: Living with chest pain

When I first met Kevin he philosophically suggested his failing bodily was a reflection of the chaos in his external world:

“I thought this is just, this is a manifestation, a physical manifestation of a bigger problem in my life which is congestion. Its rooms full of rubbish, sheds full of stuff that have never been sorted out, and now it's blockages in the arteries (laughs), I just thought this is a, this is a reflection of the outside.” – Kevin

Kevin recognised an embodied connection between his self and world. For him, the farm was an extension of self, just as he was an embodiment of it, in other words, each was mirrored in the other.

Kevin was aware that his symptoms were probably related to his heart; however, this was contrary to how most of the other men in this study viewed their chest pain. For them, “*difference*” in their body was first noted as a subtle change of rhythm in everydayness. Almost imperceptible, the men spoke of it as an altered momentum through the landscapes of their farm. Symptoms were not static in the body; they involved movement and more. Chest pain began to accompany cold weather, steep hills, and stressful situations; it was a pre-reflective experience, tied indeterminately to the farm, as much as to themselves. Indeed, and similar to Kevin, a number of the men looked outside of themselves for the cause, linking it to the inherent dangers of their farm environment:

“Well I had about four weeks short of breath, you know, but it was hot, I find when it gets real hot I do get a bit you know, chesty and what have you and [of] course you got all the pollen about, you know you work on a farm so, in the dust and everything else. I had been spraying, I had ...” – Colin

“I have often thought about this, whether it is, the lungs, farmers lungs, farmers spend a lot of time in a dusty environment just general health and safety on the farm, things that you might be doing on the farm which are likely to affect your heart and lungs and safety issues from chemical right through to dust, mask wearing stuff like that. Because ... I am guilty of it myself.” – John

Over time, chest pain became a temporal object, as distinct from isolated discomfort, durational and repetitive, creating conscious expectation, drawing the men’s attention further in on themselves and

their bodies. Body, as lived, became Jekyll and Hyde in character, all at once, visible and restricted, due to chest pain, whilst at other times transparent and free. Rather than being focussed on their project, the men found their bodies increasingly demanding of attention:

“I was milking one night and, where the computers that feeds all the cows in the parlour, as they were coming in I was tapping their numbers in (cough) excuse me, and I felt a funny sensation go up this arm, across mi chest and down that arm, and I stood there a minute and I thought, shit that was a funny thing, never had a pain like that before, it was like somebody had stuck me with an electric fence, and I just, I stood there a minute and thought, and it, I just felt as though somebody had run up behind me and stuck a bloody big needle in and sucked all m I blood out, I was lifeless...” - Harry

The male participants, portending that pain would occur, took to managing their symptoms, quietly, planning how they did their jobs around the farm, to limit chest pain and its disruption to their daily routine. Through manipulation of space and time, the men looked, in phenomenological terms, to “*incorporate*” their chest pain, thereby reducing attention upon their lived body, in order to engage more fully with the world. George gave a good example of this:

“Oh well this has been going for ... eighteen months, two years ... erm, it was always when I was doing something, you know, if I was sitting still nothing happened but, you know it er, bang! And ... the panic, you hang on to something you think, oh dear, and then after a bit it goes off ... er ... I ended up with, you know those plastic garden chairs ... up around where I regularly go, in the calf shed, er, down by the pony paddocks, tied to a gate post, erm, er, up where the rams are and the dovecote, er I had six, seven, dotted round, if I , if I suddenly

felt bad I'd sit down, erm, and then a few minutes later I'd be alright." – George

As symptoms became more pronounced and disruptive, so did the men's default way of being-in-the-world go from anticipation and an unbridled temporality, to anxious and somewhat foreshortened uncertainty:

"...some days I think oh, I'm really uncomfy here and I think shit it's like somebody's got their hand around mi heart and doing this (does squeezing motion with hand) and I just feel uncomfy some days so I tend to, if, if I get a day when I don't feel good I don't do a fat lot, I tend to rest, by the next day I'm feeling okay again..." – Harry

"...soon as I start to exert myself, or run after cattle or anything like that its, it comes, terrible and because it, it's, in the top of my chest and then my eyes and my head starts aching I thought, oh no here it goes again, so anyway, I- I steady up a bit now, just in case it goes all the way." – John

The duties on the farm can be said to exist within provisional clock-time, the seasons and turn of nature within them. However, the day-to-day activities are dependent upon an adaptability and improvisation of farm work successfully with erratic, unpredictable daily weather patterns and livestock. It was not linear time, but the vibrant, unpredictability of ecstatic temporality that became challenged by chest pain. It demanded the men measure their actions, consider rather than act and work more deliberately, if they wished to avoid symptoms. Spontaneity in the men's "*yet to be*" was diminished, sometimes lost, when circumstances deemed it most necessary, as Kenneth recollected when working with his sheep:

“You couldn’t go at your own speed you had to go at the sheep’s speed, I found that a great strain.” – Kenneth

This insult to ecstatic temporality was also an insult to their freedom, in the present, and their bodies’ ability to live in accordance with the temporal demands of the farm. Despite this, there was still reluctance to give their chest pain a name, possibly because a title would make it more difficult to ignore. However, as pain gathered itself and became more intense, so the men began to consider more prominently their body as the root cause of the problem and what that might mean:

“Well yeah, I have, have steadied down just you know, a bit, well I , phwor I can’t steady down too much, but ... erm, no that’s, that’s how I found out ... and hopefully you know (laughs) just touch wood, where’s some, that it’s not erm, bloody heart.” – John

The haphazard transience of chest pain, dependent as it was on a subtle interplay between body and world, both in terms of physical exertion, as well as responses to extremes of temperature, or perceived situational distress, all collided to create a deepening erosion of tacit trust in male participants’ body-self and consequentially their lifeworld. Increasingly, this made a number of the men feel less in control of themselves:

“I keep on working like I am, which I’ve got to work to earn a living, but it’s, it’s the unknown territory that I’m getting to, things are happening that ... I can’t control anymore ... you know, what I could control I’m not controlling ...” – Colin

As a ploughman, such as Colin, I imagine working an unfamiliar field can be quite a daunting task, fraught with potential danger from rocks and unstable ground. Colin used the analogy of *“unknown territory”* to describe his current life journey and the constant vigilance he now

faced, due to his failing health. For Colin it was as if he were entering an unfamiliar, uncontrollable world due to chest pain. In order to maintain a sense of stable everydayness he, like a number of the other men attempted to mask symptoms whenever in the presence of others:

“... now I’m getting a problem in the last six months where it’s like, thankfully Jill doesn’t know a lot but I get tight-chested.” – Colin

Theirs became a secretive and divided existence; as symptoms deteriorated, more had to be hidden. However, a dawning recognition that the men needed to seek help emerged. Despite their best efforts, they were unable to maintain their subterfuge; changes that this new state brought to their overall and extended body demeanour eddied out:

“My wife says, she said that I changed as a person erm, leading up to it as, you know, very, probably short tempered which I don’t probably erm, I don’t see that so much” - Jacob

Ripples in the inter-bodily interactions with their partner were felt by spouses, pre-reflectively, initially, and lacking any rational scrutiny, but there all the same. Their intercorporeal history, (knowing each other’s patterns of movement) implicit to their relational knowledge also gave away this change of rhythm.

7.3.2 The female partner: Bodily sensing change

The female participants experienced SAP differently from the men, although in common with them it also caused existential suffering that led to an erosion of trust in their lifeworld. Also, as with the male participants, the first sensations of disruption were bodily. Before diagnosis, the women experienced a corporeal knowing without words and, over time, sensed a subtle inter-bodily change and distancing in their husbands. These clues were experienced through a growing,

embodied sense of discord. Body disruption in the men brought about a slow and unsettling shift in farming dyads' bodily co-existence which, in turn, affected the women, corporeally.

Initially, changes in their spouse's demeanour were not consciously considered or articulated by the women; rather, they were expressed more in terms of an embodied sense of disharmony. As Janet recalled:

"I thought for a ... thought for a couple of years that he wasn't very well, and I couldn't, depending on my mood, I couldn't really work out what was the matter with him, he seemed to be awfully tired, but whenever I ever said, surely going to sleep in the afternoon for a man your age, I know blokes drop off on the sofa at night but, that's what they kind of seem to do, and I, I was beginning to think it was very strange and then I used to think well perhaps he's just getting lazy ..." – Janet

Similar to a musical arrangement, this initial change did not disrupt the pace of their whole orchestral lifeworld; but, the temporally organised and typical rhythms of their interactions began to differ, over time, which the women found disconcerting. Submerged within their dyadic flow of life, these nuanced, temporal shifts became more apparent, as their partner's condition worsened. To dance with a partner requires mutual attunement and engagement; in the same way, the finely balanced lives of farming dyads require bodily surefootedness. The women became hesitant in the company of their husbands, brought on by embodied uncertainty; they sensed change, but did not really know why:

"I'd been feeling very, erm, aware that something wasn't right and I couldn't really, unravel any of this ..." – Janet

Changes were subtle, at first; spoken of as a steady decline in their partner's vitality, a perceptible change in mood. However, this spiralled in some couples as the men appeared to become increasingly short-tempered and less communicative:

“Very, very grumpy, very irritable, and this is before it was diagnosed.” – Janet

“He can be snappy, more short-tempered ... and when he gets tired he can be a bit, a bit snappy and what not and you say, ‘oh what’s the matter with you’ ... ‘oh don’t keep on I’m tired’ ...”
– Jane

Realisation that chest pain was not going to abate unaided could have been implicit in the deterioration of the male participant’s mood. The men may have also been attempting to block interactions with partners, which might reveal their vulnerability, thereby maintaining perceived status. Whatever the reasons, during the early stages of the men’s illness, their deteriorating mood and occasional outbursts were most influential factors affecting the women’s corporeal stability. A number of the women spoke of their increasing difficulty reading face-to-face situations with their partners, in part due to their own apprehension about his mood. Despite their unease, the women tried to maintain the mundane, the habitual, possibly out of a sense of duty, possibly even fear:

“Erm, (5 secs.) ... yes, I think sometimes I’m scared he’s gonna lose his temper, he wouldn’t do anything to me, but, I don’t, I’ve never liked a lot of confrontation, not very good at dealing with it, erm, and it doesn’t happen all the time but then that’s part of the uncertainty of it. Erm, and it’s just been recently.” – Brenda

“ ... since he has been ill and what not as well like, when he’s come home and you look at him and you think do I dare speak? Cos he could be vile ... probably without realising it, but he could be vile ...” – Jane

Such interactions became problematic and unpredictable, with some of the women, such as Brenda, becoming increasingly passive towards her husband; whereas Christine took on a more retaliatory role:

“He does get a bit snappy, and of cause I’m, I’m, I’m, that’s like a red rag to a bull with me, so (laughs)... I just snap back.” – Christine

A number of the women spoke of feeling constricted by their husband’s moods and aggression. An inert body tension became the norm for them. This led some to seek escape from the farm and the claustrophobic atmosphere that was increasingly pervading their home:

“He gets grumpy, he’s very bad at communicating, because he can’t communicate in any way, he just barks out orders when he has to, and er, well I mean I’m used to it, we get on alright, we have to after 56 years (laughs), I do run away quite a bit ...” – Mary

The first flecks of an outward, relational mistrust were beginning to appear for some of the women:

“Because he thinks that if he pretends that everything’s alright I’ll think everything’s alright and I won’t worry but because you know he’s in discomfort, pain, and whatever and because he doesn’t say about it you sort of think to yourself well how bad is that?” – Jane

At the same time an inwardly directed mistrust was taking place in the men, towards their failing body:

“...you jump out of the tractor and open the gate, and that put me to my knees and you think, phew, where did that come from

that, that's you know, it's unknown territory that you don't want to know..." – Colin

7.4 Period Two: “ Going in to Hiding”: The Lived Experiences of Farming Dyads with Stable Angina Pectoris

Diagnosis of SAP brought tangible change, a true move out of corporeal synchrony. As with a choreographer intent on creating a sense of disturbance, the couples' movements suddenly became noticeably more isolated and out-of-step, despite sharing the same stage. This next section offers my interpretation of these two intertwined and yet differing corporeal journeys, as experienced by each member of a farming dyad. Despite apparent separateness, their corporeality remained inter-bodily, reactive to each other's actions; built upon the everyday coupling of their lives.

7.4.1 The male farmer: Diagnosed with SAP

The experience of chest pain disrupted the harmony of the men's mind-body continuum, and the sedimentation of thought and actions, while going about their duties. It pervaded the ambience of their world through its unwanted attention, leaping forth to disrupt the automatic flow of everydayness. The body was suddenly their focus of attention and not the job at hand, particularly when attempting to exert themselves. This, in turn, created a new articulation with surroundings, a disruption in the rhythm of their healthy *“being-in-the-world”*. The farm and its duties took on an *“unhomelike”*; there was something corporeally alien about their body and this, in turn, also made the familiar suddenly less so. Confused and concerned by this increasing de-synchrony and failing health, the men reluctantly sought a solution through a medical route.

7.4.1.1 Farmer body examined

Hospital visits, worse – lengthy admissions, brought fear for most. The corridors and clinics were a foreign land where the men felt cut-off from their usual routines and landscapes. From the bright, neon light that pervaded day, to the constant bustle of bodies, stirred by a claustrophobic spatiality and temporal insistence to be ahead of time, this was the cyclical world of the ward, the clinic, the hospital. With no recognisable reference points to anchor themselves, the men forced to stay in hospital, drifted along upon a tide of tests and empty hours:

“My biggest frustration was when I got ... you got, I got moved up to the ... admissions ward, and I was back in limbo land ... I spent five days there ... just on admissions, because nobody knew where they were going to put me ... one says, no you haven’t had [a] heart attack, another says oh yeah you have ...”
– Colin

In this “*limboland*”, a number of the men perceived that they were becoming corporeally powerless and objectified. Some were met with insensitivity, in which those tasked to provide care appeared indifferent to their needs and standing:

“... They wheel you back up and then they sit you back in admissions, on the ward, and you think, what are you? You’re nobody, you’re just sat there, give me more pills and give me more pills, I’m ... I know it’s not the nurses’ fault, it’s not the doctors’ fault - well it is somebody’s fault, their attitude is give you more pills, they shut you down ...” – Colin

It was as if Colin were lost in limbo, with nobody there to guide him, not even to blame. As the idiom “in limbo” suggests he was “*in a state of neglect; in a state of oblivion; in an indefinite state; on hold.*”(http://idioms.thefreedictionary.com/in+limbo).

For some of the men, such as Colin, the care they received felt homogenised, where personal uniqueness was pushed aside in favour of a “*one-size-fits-all*” approach. Medication given to protect their heart, caused some of the men to feel a further sense of disembodiment and lack of control. Colin reacted angrily when he was finally able to confront a Cardiologist, and voice both these concerns:

“Find me a drug that I can take, which don’t shut me down, because as I said to him, you sit in your chair, you sit there, you are good at your job, you’re a consultant, you try to help us. You are there to try and make sure that we live and that we carry on going, I said, I’m out there trying to make it that you got milk for your tea in the morning, you got potatoes for your roast spuds, I said you got vegetables on your plate for your roast dinner, even the meat on your plate for your roast dinner. I said that’s what I do. I said if I took you out of that chair and told you to go and do, go and put 100 metres of fence up, not with a tractor, not with sitting on your arse.” – Colin

The depersonalisation and lack of respect Colin endured spilled out in his defence of self. Behind his words there was a sense that he had suffered a much more protracted indignity, in that his role as farmer was not recognised. Don echoed this seeming lack of sensitivity from the healthcare workers, more reflectively:

“I think, you know, you do feel there is a lack of personal touch service and I guess that’s the nature of the NHS, it’s a ... a wheel ‘em in, wheel ‘em out type system.” – Don

When diagnosis came, the voice of medicine offered it, leaving behind bewilderment and fear for several of the men. Nigel recalled how the news was broken that he needed major heart surgery in the cramped “*portacabin*” confines that were the Angiography suite, in HCH:

“... totally devastated, er, very surprised, erm, and er, found it very difficult to accept erm, I think, the conditions they have for passing on that news is not the best erm, because you are in a very small, cramped environment, you’re in a er, one bed with another bed next door to you so you can hear exactly what’s going on between beds, and your partner isn’t there, and so you’ve got nobody to share that sudden, bombshell with er, so it, it was ... well it is a bombshell like that, it is, it does hit you quite hard.” – Nigel

Nigel felt that the manner in which he was approached lacked compassion, leaving him defeated by the news. He was surrounded by others but at that moment felt acutely alone, because nobody else there really knew him. Diagnosis brought sadness too, that his body, the tool of Nigel’s labour and worth, had let him down:

“Mentally it was a shock that my body if you like in some ways had let me down, because I thought I’d done all the right things for, for the body and somewhere down the line genetics had beaten, had beaten nutrition ...” – Nigel

The trauma of entering the world of medicine, of examination and of endless waiting, caused existential suffering across corporeal, spatial, relational and temporal dimensions for the men. They also now had to contend with a diagnostic label, which would continue to affect their lifeworld.

7.4.1.2 Farmer body diagnosed

The men became a labelled commodity, angina sufferer, someone with heart disease, the latter suggesting a long-lasting, possibly chronic deterioration of health. The doctor’s insistence on a medical discourse only left a number of the men confused:

“... They talk in too big a words that I don’t understand to start. They are not down to earth people like [us] are they?” – Harry

Most of the men found interactions with health professionals, particularly doctors, to be an objectifying experience. A number of men spoke of feeling unable to communicate their lifeworld issues effectively to doctors, resulting in the demands of their lifestyle being largely ignored. This left the men frustrated and unsure about how to continue working safely with heart disease. The same medically defined understanding of SAP was shared by most of the female partners, resulting in a relational pressure to conform to treatment regimen not always welcomed by the man. This was at odds with some of the men’s sense of identity, and became a source of conflict for a number of couples:

“Trouble is I don’t listen to her to be honest...” - John

Mary also perceptively reflected upon this:

*“Well, there’s nothing I can say or do which will make him behave any differently and just accused of nagging, (laughs)...”
– Mary*

The men in the Farm Angina Project resisted the coercion of others, even the doctors, buffered to a large extent by their strong affiliation to their farming role. However this dichotomy, between following medical advice or their own personal journey, did not sit easily with them. It led to constant worry and tension related to their actions not being congruent with how someone with SAP should behave:

“Yeah, but they just go in oh well have less (food) how can you have less. If you work hard and you are outside in the fresh air you eat more you know. Some of ‘em are away with the fairies

sometimes I think, I am not sure that the advice they give you on all these things is as good as it should be.” – Harry

7.4.1.3 Farmer body isolated

Work gave the men a sense of freedom and purposeful everydayness; they identified themselves as an integral part of their farms’ temporal flow. However, it now also brought with it inherent peril, above what had always been acceptable, as the men acknowledged their diagnosis and its “corporeal implicatedness”, i.e. they recognised whatever happened to their biological body invariably affected their “lived body” self. This frightened some, particularly those whose symptoms were worsening. For them, what was once just “a bit of chest pain” was now a warning sign of something potentially more serious, such as a heart attack;

“... soon as I start to exert myself, or run after cattle or anything like that its, it comes, terrible and ’cause it, its, in the top of my chest and then my eyes and my head starts aching, I thought oh no here it goes again, so anyway, I - I steady up a bit now, just in case it goes all the way.” – John

A number of the younger men experienced an increasing sense of isolation, due to their SAP. This strange solitariness pervaded all aspects of their existential lifeworld, the corporeal, relational, as well as spatial and temporal. Suddenly, the peaceful solitude of the fields took on a more foreboding loneliness:

“You spend a lot of time sat in the tractor cab on your own, where you don’t see nobody, but we’re used to it, it’s what we do, you know ... I suppose we are isolated to a certain degree ... especially on a big farm ... but, it’s what you’re used to, you know you get used to it, it frightens me now more ... working on my own.” - Colin

This led some to reflect on how the number of farmworkers had decreased, due to the advent of new technology and modern farm practices. This made them lament the lack of work-mate camaraderie which, together with SAP, now added to feelings of isolation in work:

“Everybody would help one another then and you had a bit of a laugh amongst yourselves at work, but as today if you’re a cowman on a big herd, nine times out of ten you’re doing it yourself, so you don’t see anybody and that’s just how it is, it’s become more isolated as the years ... have gone ...” – Harry

Once faced with the spectre of heart disease, it appeared that the men continued to find illness difficult to communicate. There were no past reference points upon which to build a view, other than the experiences of a few elderly relatives; these stirred a mix of emotions, from alarm to a certain inevitable acceptance:

“Well I thought I was going to snuff it, I thought it was a heart attack, because that’s what my father died of, and a, I can see it now, arrhh, bump, dead.” – George

“It’s been in my family as long as I can remember, gran had heart trouble, and a lot of angina, Uncle had angina, died at 42, erm, so it’s some’ at I’ve always been around...” – Harry

SAP did not fit into their routine or dialogue; the doctors spoke of it in a language that was not of their lifeworld. The actions offered regarding the management of SAP were a perspective they did not know, or wish to concede, in the early days after diagnosis. Certainly, they did not tally with the physical requirements of running a farm, or offer any strategies for maintaining their work role with it.

The surprise shown by their partners at the news that they had heart disease reflected an uneasy change in the way the men considered others now perceived them. For several of the farmers, it was as if they were suddenly failing to be themselves:

“She was as surprised and shocked as me, and because I’ve always been a little dynamo doing a lot of work around here ...”

– Nigel

Most of the men recognised that the support of their partner was beneficial and, in some cases, became the driving force behind them accepting the need for professional medical attention:

“No, I think in my case it happened fairly quickly and I did own up to it, mainly to my wife who is in fact the driving influence to get something done about it.” – Kenneth

However, the majority still voiced a reluctance to discuss or demonstrate limitation, due to SAP, in front of their partners. There were three main reasons given for this. The first reason was that they did not want to worry their partner, unduly:

“I hide a lot from Jill because, she, at one time she wouldn’t sleep, you know because she was half sleeping making sure that I’m still alive like, you know, she was worried that I was going to die you know ...” – Colin

“...my priority in all that is that I really don’t want them hurt or upset. I care less about myself than I do about them in a way.”

– Kevin

The second common reason was a wish to avoid their partner’s attempted coercion or control regarding their lifestyle. Certainly, this

was a feature of a number of the participants' relations, during the early stages of diagnosis and treatment. The men tended to maintain a strong lifeworld perspective of their illness, compared with their partners, who tended to take up a more medically informed stance. Therefore, many of the men saw their female partner's view as contradictory to their own, particularly with regards to farming duties. This difference in illness representation was divisive for some dyads, causing arguments and added stress:

"... She tries first of all to tell me quietly and then it's, its nagging ... which I don't take too much ..." – John

Linked to this, some of the men voiced that their partners did not understand the farming way of life and so found it hard to accept their actions, seen as now unreasonably risk-laden:

"She would have been better off knowing that I was going to an office and that I was just going to sit down with a pen and answer phone calls and I would have been home at 5. It would have been ten times better for her that would have been." – Colin

This led a number of the men to feel more relationally isolated from their partner due to SAP. Their corporeal withdrawing, particularly an absence of closeness, along with increasingly poor sexual relations deepened their sense of body-self alienation and failing prowess:

"Eighteen years we have been together and for the first sort of fifteen years intimate sexual relations were very, very frequent, almost daily for that length of time which I found astonishing, um, things kind of declined, not declined but became less frequent um in the last, couldn't really say, Louise would probably remember better than me, it's hard to remember, but I would certainly say the last two or three years erm and since

last year, since the heart condition problem um, one thing I had noticed is, um, erectile dysfunction is more consistent.” – Kevin

This was not something the majority of men felt comfortable discussing with their partners and, again, appeared prepared to live with, rather than seek support.

“I have never been really right sexually since, it’s not the biggest problem in life; I got two sons so... it goes in the melting pot with everything else. At 66 I shouldn’t expect too much in respect, but I have always enjoyed (laughs) that part of life put it that way. I am not ashamed to admit it.” – Don

Jacob spoke about his vulnerability due to heart disease, and how, in this weakened state, he tried to hide it from the wider farming community, to avoid embarrassment. This also challenged his sense of self:

“I do feel sorry for myself erm, erm, I would probably be quite a bad patient erm, I’d come back from it and feel quite upset, erm, that what’s happened to me, erm, I have, er, been in tears, erm, which, erm, being a rugby, football playing businessman is something that I would not say or admit to, to anybody, but I am saying it has happened.” – Jacob

Indeed, some of the men avoided town or other social situations altogether, during this period, so that they did not endure the indignity of being seen to be struggling with illness. Colin withdrew from family activities, because he wished to protect “them” from his illness. This left him feeling spatially trapped, hiding out in the fields that he also now feared:

“I got to work today means they’ll go to town, they still go and do what they got to do, but ... you’re not putting them at risk to

what will happen to you, I know some people would see it as selfish, but are you selfish or are you trying to protect your family, yeah, I'd like to, I want to go on holiday, you know, I'm frightened to go on holiday because I don't know what is going to happen." – Colin

Colin, in particular, found it difficult to live with his diagnosis of SAP. The central role that his body pertained, due to illness, caused him to feel almost "exiled" from his world. For him, the open fields were now isolated and dangerous; Hereford City Centre more so, due to the claustrophobic gazes of others upon a body-self beyond his control, which might let him down at any moment. He avoided trips out with his family, because their presence heightened his anxiety and unstable body state. He voiced concern that he might falter in front of his children, embarrassing himself and frightening them. Colin found it difficult to demarcate between where his body felt comfortable and under threat. His tractor cab appeared the only place he did not perceive a body out of control, but leaving this haven, to move rocks while ploughing was also not without danger now:

"I did three hours Sunday finish off a bit of ploughing over the one field thought crack that farm up, and you, jumped off and opened the gate and it put me to my knees, just like that and you think, oh, that was different where did that come from like, you know, and you begin to think hang on here a minute, this is ... this is unknown territory..." – Colin

As mention earlier, Colin spoke of entering "*unknown territory*", with SAP and was fearful that he might die, at any time, due to it. Colin's experiences highlight how the proximity of others, charged his angina state and gave it a volatility that he did not suffer, when alone. However, in being alone, he risked not having the assistance of others

ready to hand, if required. Again, this paradox between world and body was repeatedly expressed in his narrative.

7.4.1.4 Farmer body limited

Despite all this, SAP became an accepted reality for some of the men over time; they began to accommodate to its limitations and one participant even voiced some satisfaction in overcoming the difficulties it posed:

“I’m quite happy downstairs (laughs), but er, it’s very convenient, you know, erm, you know, I’ve got er, there’s one very big room, it’s oh 30 foot by 20, oak beams, huge ... ingle fireplace, and er, I’ve got m[e] music centre, m[e] tele, settee, m[e] bed, er, computers in one corner, everything I wants in there, and it’s just through one door into the kitchen ... easy (laughs) and I don’t have to go, doing a lot of housework in the rest of the house, except for knock the cobwebs down maybe ...” – George

Octogenarian George worked hard to maintain control over his lived space (e.g. by placing plastic chairs around his farm; sleeping downstairs etc.). He did this, so that his ability to work the land and tend his sheep was not halted, in this way maintaining a certain adapted freedom. In George’s case, his wellbeing was tied to his ability to dwell at home, including work on his farm, and appreciate a felt sense of this experience, in spite of SAP:

“...people keep saying, you should retire, what would I do, you know, I’ve got weekends doing my carriage driving, but the rest of the time, what would I do? I’d be bored out of my brain.....you know, unless I can get up and go and have a look around the sheep, erm, or hitch a pony up and go for a drive round the sheep,....erm, I’d be lost...” – George

Diagnosis brought a rupture in all the male farmers extended, embodied sense of self, a fissure between their body, others and the farming landscape. Although it did not limit everything, its detrimental effect on their perceived freedom placed tension across the whole existential web of their lifeworld and natural attitude towards trust within it. Some, such as George, adapted their lifestyle to SAP, in order to rebalance their sense of trust, hope and journey, whilst others, (such as Colin) were less accepting of their illness and so continued to find its imposition upon their freedom difficult.

7.4.2 The female partner: Experiencing diagnosis

Just as the men experienced a destabilising of their lifeworld, due to a SAP diagnosis, so too did the women. Routine embodiment was tipped off balance by the shift in their husbands' state. Their felt sense of the other's discord, through their inter-bodily resonance, attuned over many years, was suddenly and starkly upheld by events beyond both their control. Each of the women now sensitised to their partner's SAP became divided in themselves; to maintain independence and free movement against a pressing obligation to fall into step with the rhythm of his illness.

7.4.2.1 Partner body wounded

Diagnosis wounded the women; they spoke of it in such terms:

"... that has been very wounding emotionally to see your partner go through something quite as painful as this." – Carol

"...they did the angiogram, said you know you've got two really blocked, and one of them is nearly completely blocked, that, that was a time when I really thought oh my god, this is, I felt really awful about that, really sick, really wobbly." – Janet

Crying in the car park, feeling dizzy and having to sit down, this is how the man's heart disease entered their lives:

"I left the hospital and gone and sat in the car crying and crying... (8 secs)... you feel helpless... I will never forget the one day he turned round to me and said, you don't know what it's like, it's not you it's happening to, and I am thinking, yeah it is..." – Jane

They struggled to grasp what such a diagnosis meant, being somewhat alone in trying to understand the seriousness of it. The impact of what their body had sensed before words now meeting conscious recognition with a thump of revelation; the rollercoaster had begun, with its first customary stomach churning drop:

"I suppose it has been a roller coaster of emotions. Um, from early days of not knowing the extent of what was going on, to imagining the worst because I couldn't go down the middle road, cos I am not, I don't tend to be a middle road. I am either one side or the other, um, and um, and yes, and trying to lead a normal life ..." – Alison

The news of their husbands' illness brought with it guilt, in some cases, that the women had not acted upon their bodily "*hunch*" regarding their spouses decline. For others, the fact that they had not seen the illness coming also made them somewhat perturbed by this lack of attention. A realisation that their husbands had hidden symptoms from them led to growing mistrust within some relationships, particularly for the non-farming women.

"I thought then, you know, this is, you know, not erm, you know this is a problem that needs looking at erm, but on reflection I think he's probably had it a lot longer than he probably realises, erm, and hasn't said anything, and hasn't done anything about it either." – Christine

“You have to watch him like a hawk...Like having a little two year old sometimes.” – Jane

Despite similar illness beliefs, the women who worked on their farm appeared more circumspect about the dilemma illness brought and less fearful of the potential hazards their husbands' occupation posed:

“He’s fine, you hear people bouncing round like they’ve got a new life, that has kind of lulled me into a sense of security that might be false or might not be, and then on the other hand we do have an air ambulance, erm, and because we are only five minutes away from the A94, you know, and I can drive, a tractor and a quad bike you know, land rover, you know, so maybe I over-estimate my abilities, I don’t know and I do think I know the difference between somebody who erm, isn’t having a heart attack and who is ...” – Janet

The women who did not ‘farm’ held the view that their men were being reckless in trying to uphold a commitment to farming, over their own health needs now that they had heart disease:

“You can see what it’s doing to him, but he just won’t admit defeat. If he doesn’t get out it will kill him ... and that’s what I truly believe ... (crying) ...” – Jane

All of the women believed that a diagnosis of SAP brought with it the increased possibility of their partner’s death, due to heart disease. This caused existential suffering, as the comfortable conformity of their lifeworld was unsettled by the introduction of such a serious illness. The health professionals involved in their husband’s care did little to cushion the impact of such news, as Carol recalled:

“... [That] he was told such serious news on his own upset me a lot and I felt that we should have, they should have arranged for me to be there to hear it with him because when I did collect him I was rung twice to come quickly for him and I just felt that was a bit incongruous having been told to leave him all day, so then when I did pick him up and said was everything alright, as we went out to the car, he obviously said ‘no it’s not’ and he had been given this quite serious, you know, prognosis and decision about what had to be done.” – Carol

Still reeling from diagnosis, their husbands became the women’s primary concern; however, the body hesitancy that had built up prior to diagnosis became even more polarised for some. Brenda, who had struggled to come to terms with her partner’s increasing bad moods, now found it difficult to consider how she might help him:

“... (7 secs.) It’s ... (sigh) I - I am at a loss really to know what to do about it ... this is not the same as he used to be ... (5 secs.) ...” – Brenda

This left her feeling a cascade of emotions, ranging from guilt, anger, frustration, lack of control, to, ultimately, an embodied sense of loss. As with all of the women, she conceded becoming increasingly vigilant about what her partner’s body was communicating, necessitated, in Brenda’s case, by his continued lack of open dialogue.

Diagnosis spiralled all the women into a new phase in which their lived body receded behind a timetable of pressing duties, created by illness. These involved caring for their husband, maintaining family routine, as much as possible, and in some cases working on the farm.

The women now faced the loss of their stable, taken-for-granted lifeworld, and their role(s) within it, for a more volatile and uncertain landscape due to SAP.

7.4.2.2 Partner body sacrificed

Not all the women in the study lived or worked on a farm. For those who did, however, their partner's illness led them to be more physically active upon it. The women engaged with this, stoically, seeing it as a requisite of maintaining family farm equilibrium. Resultant injury and fatigue from this additional work were quickly dismissed by the women. They practised body disregard, seeing the men's physical needs as more important than their own:

"I did all the mucking out of the horses, so I got incredibly fit ... and quite tired sometimes." – Janet

"I have felt quite strained at times, and quite tired because I realised I was sort of feeling as if I was having to carry everything you know at first obviously..." - Carol

Molly's story was particularly graphic, made more so because she is in her 70's:

"... now Christmas day was serious because I er, it was frosty and, and them two fingers there and them two because I've got arthritis I've got to have my fingers out in the gloves you know and they stuck to the wheelbarrow and I had all new skin and I couldn't eat, erm, dinner on Christmas day because it had all come off ... oh it was a hard winter here, I never had that ever to happen ... and all my skin was in my gloves and on the wheelbarrow ... them there, red hot, and were all new skin on them ..." – Molly

Self-sacrifice, internalising problems, absence of self-care were common sub-narratives:

“I don’t want him to worry about the things that I’m worrying about and why I’m worrying, so in a way, I sort of like carry it all, and, it’s very difficult really ...” – Christine

“We had a lot of bad days, you can tell as soon as he comes in, his breathing, the colour of him, how clammy he looked and he had a bad day. ‘No I’m fine. No I’m fine’ and he won’t admit, it’s not defeat, he won’t admit ...” – Jane

Here, Jane highlights the difference between herself and her partner; she describes his failing condition in graphic terms and then juxtaposes this with clipped comments regarding her own stoic resolve. Yet, her use of “we” gives away something of the conjoint strain of SAP. Later, in the same interview, she alluded to the embodied burden of responsibility weighing down on her:

“Just about everything is on my shoulders. I am not allowed to fall apart, because if I fall apart the whole parcel breaks down.” – Jane

Covert guarding of their partner created an inner body tension which the women consistently ignored, during the early stages of his illness. However, this inner state of alertness was a constant, whether he was in the home or out on the farm. The narratives of a number of women gave harrowing testimony to this:

“I was frightened he would have another one, umm, yes, but, yeah I am always watchful over him, always cos I do most of the stuff, domestic stuff, and making sure he is okay. Yeah, and I make sure I try not to stress him but it’s quite difficult really.” – Brenda

“He lays in bed and you can hear him breathing and you think is that his last breath, because it’s sort of and you can really hear him rattling, it’s as if, for want of a better way to put it my grandmother bless her, she died of pneumonia, she had bronchitis pneumonia when she died and erm, went in to see her the night before she died and she had what they call, years ago I presume they used to call like the death rattle in the throat and he, he sounds like some nights and I sometimes think don’t want to go to sleep ...” – Jane

The thought of lying next to a dying partner, hearing their last strained breath, brought to the bedroom a suffocating intolerance of sleep for some of the women. Instead, body tension and ragged fatigue held those, such as Jane, rigid in the darkness, while her spouse slept.

7.4.2.3 Partner body alone

Just as it was for the men on the farm, lived space became an isolated vista, defined by a temporal uncertainty and aloneness, in the present, for the women. A couple of the female participants, such as Jane, appresented how their partners were coping out on the land:

“He’s blacked out, when he was in a field on his own, luckily he wasn’t behind a tractor or anything, down by an irrigation pump trying to get that down but, saying that it’s by a river, he could have fell in, he could have ...” – Jane

In doing so, they found their suddenly solitary lives within the farmhouse intolerable. Anger and fear rose up in equal measure, within this now hostile world, magnified by their spouses’ absence and fear for his safety. Jane, in particular, found that the home became a solitary waiting-room, where she endured uncertainty regarding her partner’s safety. Even though Jane was bodily at home, her thoughts were traversing an imaginary representation of her partner’s work-landscape.

Powerless observer, in her mind's eye, she nervously watched her partner risk his life undertaking dangerous farm duties. As a consequence, Jane lived in constant fear of receiving bad news about her partner:

"It was like being on hot coals every time the phone rang ..." – Jane

For Jane, this constant journey into a threatening place fuelled her anxiety, concerns and even anger towards her partner for risking himself within it. This led her to escape the house, in order to distract herself from these fears.

This was not the case for all partners. Carol reflected with humour her spouse's hesitancy returning to physical activity, on the farm, with heart disease. Although she acknowledged his concern, she did not quite share it:

"Well yes and no, on two occasions I have actually told him to get up and (laughs), because he really took to heart this um, saying I think you gave him, or along the line he picked up that if he wanted to do something to halve it and then do less than half, to the point that he was sitting around saying well I can't do anything ... and I said well you can, you just have to (laughs)." – Carol

For Carol, appresenting her partners' work was not something she had to do, as they worked alongside each other on the farm. As a consequence it appeared that the haunting stress of his welfare was not nearly as prominent.

Significantly, many women found it difficult to communicate with their partners, at this time, and so did not feel the same level of support was available to them from their spouses, during illness. A number of the

women reconciled that their partner's reluctance to share his feelings about his illness was done with the best of intentions:

"No, no, as I say he doesn't talk an awful lot about it because he, he, in a funny sort of way was trying to protect me from it, erm because he knows that I'm a worry freak, I will, I will worry erm ... I can't help myself in that respect, hmm." – Alison

"Because he thinks that if he pretends that everything's alright I'll think everything's alright and I won't worry." – Jane

However, this lack of communication with partners fed their distress and uncertainty, which a number of the women endured silently. This caused the women anxiety and added to their perceived need to supervise, coerce, and even try to direct their partner's activity levels, in order to protect him, whilst limiting risk within their own lifeworld:

"I mean you know I keep, I suppose a quiet eye without realising that I am doing that and without him realising, but it's important that he doesn't realise because otherwise he gets cross because he thinks I am watching him all the time you see." – Alison

Jane, in particular, was affected by a loss of relational trust during this unsettled period. A number of times she talked about her partner in the past tense:

"This is going to sound awful, but the guy I met sixteen years ago is gone and now he's got health issues ..." – Jane

During early interviews, there were examples of narrative foreclosure. Jane's relational story with her partner appeared no longer sustainable, due to her loss of trust and, with this, her on-going commitments to this

particular life narrative. Indeed, Jane did leave her partner, before the end of the study.

It appeared that both members of farming dyads had difficulty sharing vulnerability with the other, during the early stages of SAP; the men, because they did not wish to be seen as anything other than capable of maintaining their farm; the women, because they felt duty-bound to uphold the role of care-giver and thereby not trouble their partners with any of their own issues, during his illness.

Similar to the men, the women were protective of their privacy and current circumstances and therefore did not court the support of others. A couple of women confided in their sisters and / or close friends, but the information they gave them was closely censored. Different people were afforded differing levels of trust and therefore information. Siblings remained protected from their current ordeal, as did other family members, where possible:

“I didn’t tell them, I just couldn’t for some reason, I just couldn’t bring myself to it, which is wrong really, because you know, we shouldn’t really be protecting them because that makes matters worse for them if something terrible should happen you know, um, I don’t know why I did that.” – Alison

Christine did approach the parents of her husband, only to find that her worries were not met with the same understanding or concern:

“Jack’s parents never really talked much about, about it all, so, you know, I did approach the subject with them once, I can’t remember where he was erm ... w- how come he, I don’t know where he was any way erm ... yeah and I just thought oh that was a non-starter you know they didn’t seem to want to, I thought they, I don’t know, I don’t know what I expected from them really but I just felt that it wasn’t, it, the conversation didn’t

go the way I wanted it to so I said 'oh well', so I didn't pursue it ... erm ..." – Christine

This led Christine to draw away from her partner's family, which only served to make her feel more isolated. Intriguingly a couple of the women confided that the only person who had given them an opportunity to speak was me, the researcher:

"There has never been an opportunity; there has never been an offer. I mean you are the only person who comes here that we talk to about this, I haven't spoken to anybody else, nobody, if there is a facility out there I certainly don't know about it." – Alison

Even though many of the women appeared remorseful at not having a confidante, this did not stop them dutifully protecting their family privacy. This may be allied to farming identity (in some ways shared with their partner), as alluded to by Christine:

"I suppose there's an element of pride isn't there and also for Jack, I don't want everybody knowing his business, erm, so I suppose we're quite private people really in that respect, and that is probably ... and that stems, I suppose from my upbringing as well because I've felt that we've all been quite a private sort of family..." – Christine

As the news of their partners' condition inevitably became public, certain women reflected almost indignantly how their wellbeing was ignored by a growing number of well-wishers from the local community, as Carol recounted:

"I got sick of everybody asking me how he is really, they very rarely ask you how you are (laughs), I think most carers find it ... Hmmm" – Carol

For the women now, hope pinned itself upon effective medical management and a return to some state of relieved stability.

7.5 Period Three: “The Returned and the Invisible”: The Lived Experiences of Farming Dyads after Stable Angina Pectoris

First, the men experienced transient discomfort across the chest, often in cold weather or during exertion on the farm. Over time, this became a repetitive line of incidence. As intensity, repetition and functional concerns grew, so a medical viewpoint was sought. The subjective world of chest pain for the farmer became the objective world of heart disease for all, following a diagnosis of SAP. The corporeal disruption to their existential lifeworld that this caused, as well as their partners, was described in the previous two sections. This final section details the experiences of participants, following successful treatment for SAP and / or learning to live with it. It charts the men’s recovery from intervention, a steady “*return*” of their body, and themselves to the farm; despite perceived limitations due to diagnosis and the medical regimen they were encouraged to follow. I then describe the difficulties their spouse’s had upholding a clutch of commitments to their ill husband’s, the farm, and other responsibilities. I evidence deterioration in their wellbeing due to the strain of these multiple roles, and the body denial and “*invisibility*” they practiced trying to maintain existential equilibrium.

7.5.1 The Male Farmer: Treatment for SAP and beyond

The time came. For most, stents or bypass? The male participants recounted how they lay passively in hospital, feeling powerless to intervene, “*body object*” in medical terms:

“I sat reading and one of the nurses was quite chatty so that was alright and ... as long as you don’t think about it, you go into that operation, you lie down, now here goes, but I mean you have got no choice have you really, you’ve got to have something done or you end up in a mess.” – Harry

7.5.1.1 Farmer body treated

Eventually, and with varying degrees of post-operative impediment, the men returned home. This was the worst time for some. Firstly, there was the fear of leaving the safe confines of the hospital, despite their reluctance to be there, in the first place:

“Um, it was just when you come out and you’re sitting there and you think shit I got to go home now you know?” – Harry

“...nobody will ever know how down you can get, coming back from hospital and not having the safety net of the nurses and doctors around you” – Jacob

Incapacitated by the trauma of surgery / strict instruction, and being confined to their home, the men found this disarticulation from the farm then difficult to bear. Jacob found not being able to feed his own cattle a painful, double indignity; experientially, by failing to uphold his own ideals of self, and relationally, by having to ask his elderly father and neighbour to help, making public his vulnerability in the process:

“I could hear coming back from hospital erm, the animals shouting of a morning for their feed, as normal, at half past seven in a morning when I would normally go out and feed I wasn’t able to erm, so my father erm, who still lives on another property on the farm, erm, but is retired had to erm, get a neighbour to come and feed them but he still had his cattle to feed so the neighbour didn’t come until ten o’clock erm, but

knowing that the animals hadn't been fed until then was a very stressful time." – Jacob

This inactive body state was foreign to the men, more than just in the body, it was as if their extended body had been amputated almost. Many found this intolerable:

"Yes, not being able to do nothing yeah, I've never had this in my life ... never been off in my life, never missed a day's work in my life ... don't think I've ever been in bed for a day in my life. I find it very stressful I tell you that." – Arthur

The present stretched indeterminately, as if stuck in a temporal sick role stasis:

"I'm getting bored like this, I will tell you that now, I'm getting really bored ... if I'd think I was near a pub I think I would end up drinking." – Arthur

Early on in the men's illness journey, medication was given to help alleviate SAP and protect participants from the risk of further cardiac incidents. Initial consultations with their GPs led most of the men to be prescribed Glycerol Trinitrate (GTN), which alleviates the symptoms of SAP by acting on the coronary arteries, widening them to increase blood-flow to the heart muscle. Use of GTN became a regular practice, before embarking upon physically demanding activities, as the men got to know what exacerbated their symptoms. Taking this drug was seen as necessary to maintain their freedom to act. This incorporation of GTN occurred over time and through repetition and habituation:

"I noticed by not having angina and by walking up steep hills was unbelievable, you know, I probably stopped three or four times up a steep bank, which is I don't know, 150 yards from top to bottom, maybe 200 yards from top to bottom, but when

you stop and use your spray and go again and you get to the top and you're alright but you know you got angina a little bit and its going 'cos you have had your spray, I mean for the last two weeks I been up and down the banks never used the spray and never had any trouble when I got to the top. I been a lot fitter now." – Harry

As SAP was alleviated through other interventions (PCI, CABG), so the men slowly let go of this ritualistic reliance. However, participants remained wary of its return and most hung on to their GTN spray:

"Oh I haven't touched my GNT spray for oh, it must be 2 months now...still carry it mind."– Colin

All the men felt that their prescribed medication (other than GTN) had a detrimental effect on their "lived body" experiences. Common side effects were discussed and included general tiredness which affected their work rate on the farm, being more sensitive to the cold, and problems linked to erectile dysfunction. Most of the men, such as Don, accepted these side effects as the lesser of two evils, in their ongoing wrestle with a body now unpredictable, due to a diagnosis of heart disease. The fact that his comments below are twelve months apart is telling, in this regard:

"Sleepiness, how much is that old age and how much is the pills I just don't know." – Don

"The pills disrupt, they don't do much for your sex life, I will tell you that for now." – Don

The impact of erectile dysfunction, a noted side effect of beta-blockers, was not discussed in detail by any of the men; other than a brief jocular comment. However, I could only surmise that a certain body isolation

and loss of body integrity must still have haunted those men who were experiencing problems.

The practice of tailored adherence (i.e. where participants take their medication, but not exactly as prescribed) or more drastically, non-adherence due on unwanted side effects, was commonplace:

“I changed my diet, erm I was very careful about sitting down after a meal, and ... I cut everything out I thought was bad for me in terms of cholesterol or whatever I had problems with Atorvastatin to begin with, I was on 80mg I actually cut that right out because I didn’t like the effect it was having.” – Kevin

“... why’ve I got all these pills rammed down my throat and, they’re stopping me doing, anything, so you ask the question, oh well, they, they are given you for a reason because you’re ill ... you can start taking them now, and you start taking them and you can’t walk ten yards, and you think well, being farmers, you know we’re physical people, what do you do, oh we shan’t take that one, we shan’t take that one, we shan’t take that...” – Colin

The side effects of their medication spoke to a number of the men of a body still alien, to some degree. This perceived negative effect led some participants, such as Colin and Kevin, to attempt to re-territorialise their body through self-selection of the drugs they were willing to take. In this respect, the judgement of their prescribing doctor was not trusted. The men felt that the doctor did not understand the requirements of farming, demonstrated by the drugs they were given. Their reactance against the advice of the medical world could be seen as a symbolic stance of independence and attempt to re-establish control.

7.5.1.2 Farmer body temporality

Our lives are usually a flow of uninterrupted tasks. We are born into this flow and begin to swim along with it, almost immediately. However, life is not just a succession of isolated actions and events. Tasks are always implicitly or explicitly linked, each made possible by its predecessors and consideration of tasks to come. It is this sense of flow that can make vivid or distort one's sense of time, when there is disturbance.

The "sick role" that accompanied medical intervention was one most of the men did not know and it tested their sense of self, due to the hiatus it caused in their task- orientated and temporal farming world:

"I think my mood would have been worse if I'd been stuck in the house and couldn't go nowhere, at least I could go outside and blow it off a bit....or I could go in to the workshop if I only walked round and looked at this and looked at that it passed my time, because otherwise if I'd have sat in this house or nothing....and the pub was four doors down the road I think it would be dodgy! (Laughs)..." – Arthur

"I was about a week mulling things over, thinking oh shit, why did it have to go wrong so quick but I suppose you've got heart trouble you're not guaranteed on how long you are going to live or any time, nobody is are they so, it's just one of them things you think about it a bit and then oh well I'll carry on now as before regardless, and hope that it turns out alright erm, who knows, I wish I had a crystal ball sometimes bu...it concerned me for a week or two and I thought, nothing I can do about it so I may as well get on with my life." – Harry

The lived space of the farmer can be said to be temporal, constantly changing, unlike a static place, like a hotel room. Cyclical

transformations of the farm landscape take place throughout the seasons. Although spring officially starts on the 21st March, it does not herald the start of associated spring time duties on the farm. It gives only an indication of nearness of change. Rather, the seasons gradually merge into each other, but at each threshold there is liminality that impacts the lives of those who work on the land. This is important to acknowledge, when considering the spatio-temporality of the men recovering from SAP. The time of the year did appear to influence the farmers' mood, colouring how they viewed their lives, linked to their present incapacities, as Kevin colourfully described winter:

"...its grey, it's you know, erm, this time of year to me, it can be if it's really grey, it can be...like a vision of...er...of pointlessness and death, death all around you because everything is dead, you know, and it can be a bit too quiet." – Kevin

"Well, summers are nice times, you know you've got the lambs growing you've got...hay, I love the smell of cut grass and erm, all around I've got a load of Buzzards and you see them flying around in the summer, er, no it's nice, and then winter comes and it gets a bit depressing..." – George

I can imagine no place in which this temporal change is more apparent than on a farm. Indeed, the change of season from winter to spring marked an important time point for most of the male participants, against which any progress regarding their SAP would be measured, in the coming year:

"Hmmm (5 secs.) well ... within the next, next six months before the next winter we've got to decide whether we can or want to cope with ... what we do here, and whether it's physically possible to do it, you know, to, there's got to be a

degree of realism about whether we can carry on as we are working.” – Kevin

The seasonal demands of their farming year stretched out in front of each of the men, creating a pressure to look beyond themselves, as soon as SAP relented, or could be adapted to.

7.5.1.3 Farmer body supported

The men who had bypasses were offered CR; however, most were reluctant to take up the offer. Difficulty accessing the programme was a common reason, although for Harry, his GP was also complicit in him deciding not to attend. When asked what the GP had told him, he mimicked:

“... You’re probably doing enough exercise on the farm already.” – Harry

Other participants, including Colin, thought that the programme would not cater for their needs, serving only to take them away from the farm during important seasonal duties, such as lambing in early spring.

A number of the men found the county’s acute and primary healthcare services intransigent and inflexible to their needs:

“I think there’s a fundamental, from a time and motion study point of view, not even from a man management point of view, I think there is a fundamental flaw in the system. It is certainly a waste of time as far as I am concerned because if you pay to park the car in Hereford you just as well get it all while you are there and know exactly where you are going. Without having to come home, make an appointment, go back into surgery, waste more time, at a time when the doctors say they are overburdened. That’s my view.” – Don

Some of these men lamented how their local GP used to be someone who knew something of their history, their family and who understood the farming way of life. They found that many of the new doctors lacked the cultural sensitivity of their predecessors, leaving them feeling isolated by a lack of continuity or understanding:

“You never see the same vet twice, and I think it’s really bad, I mean it is something the GPs suffer from and if you want to see that doctor you want to see you have got to wait so I do yeah ... because I think that is very important, I know it’s a nightmare to cope with scheduling...” – Kevin

“I go in there and I don’t, I don’t spend 10-15 minutes chatting to him like I used to, erm, it’s probably 5 minutes, erm, and it’s gotta be fitted in although I do make sure the questions I want to be answered are there before I go and see him because that’s, over the years you know, I’ve gone in there and it’s how’s your mum and dad, and those of the family and my sister, but it’s gone, it’s like any other business he’s so busy.” – Jacob

This left a number of the male participants keen to end their association with care services, as soon as possible, regardless of any remaining illness uncertainties they might continue to harbour. Colin was able to reflect that CR may have been beneficial, had it been able to target the needs of farmers, more specifically:

“I wish ... part of me wishes that I had actually took more help than what I did, you know like, come to your rehab clinics and what have you. I think part, it suits certain people right, but it needs to have, how do you explain it, it needs something there for other people, you know, yeah I come, which you do and I hadn’t actually had a heart attack, I can understand a lot of things you do, you go in there, you learn to relax, you do your exercises on the board. That’s all well and good, but it’s

actually being a farmer, it's sort of we can do without that, yeah, that's not for us. But if you actually went in there and um, how do you put it, if you actually sit down and talk about what was going on in your life um, how you can learn to relax, some ways I think it will pay if, it don't happen, but like yourself or some of the team could actually go out and see what it was like on a farm, you know, what actually, if they spent 2 or 3 days on a farm and actually saw what farming life is, then you would get an understanding of what sort of person you are dealing with, cos it's, unless you actually go and do it you don't understand it." – Colin

This was a powerful observation related to Colin's belief that a more lifeworld-led approach to his rehabilitation would have provided more effective support, particularly one that might have helped him to maintain a certain resilience in his work despite SAP.

A couple of the men reflected that their GPs were supportive, underlining the differing experiences, in this regard:

"The medical support I get from the GPs down here is very good, I think I mentioned that, and the nurses is very good, erm, it seems that you have only got to ring up and say that you are a cardiac patient and you get a quick appointment, you get, yeah so, and they have been very quick at consulting the consultants in, or asking questions of the consultants in the cardiac department, so yeah I feel okay there." – Kevin

Again, two of the men who attended CR were also able to reflect upon their experiences, positively:

"I am just very pleased with the help and everything I have had through the rehab team and the way it's gone and the way they wanted me to go onto the halo scheme and the help I had there and right the way through." – Jacob

“Very useful indeed. It gave you the breadth of understanding and sympathy which I found very helpful, you know I would stress the sympathy I thought they were excellent.” – Kenneth

Jacob and Kenneth found the “*sympathy*” and support they received in CR beneficial. Both found the programme’s focus upon practical fitness matched their view of the body in everyday life, and allowed them to realise that their bodies were, indeed, corporeal capital that helped them to maintain their positions as farmers.

For all, time passed and as SAP relented (for all but two of the participants), so were the men able to contemplate that heart disease appeared no longer part of their immediate lives. The hill became suddenly less steep, the sheep less swift, as a return of their previous capabilities blossomed:

“Well it’s um, typically the thing of [? word] walking fast or walking up hill, um, I soon had to use the triglyceride but I haven’t tried the triglyceride since and I have walked up the same hills rather faster.” – Kenneth

With this return to everydayness came fresh hope and deliverance from the confinement SAP placed around their lives. However, the threat of heart disease still cast a shadow over this renewed intent, and left them less trusting of all which had once seemed so assured:

“Oh...well it’s alright at the minute, you’ve got to live everyday as you can, can you, it’s no good thinking 6 weeks advance and then you have a heart attack and die is it? Hey...I take every day at a time I do, its erm...that’s what I do...” – John

7.5.1.4 Farmer body returned

During the twelve months of the study, the men endured “*lived body*” destabilisation, characterised by an alienation from their bodies, disruption to their body project, i.e. the farm, and subsequent sense of a loss of control this state imposed. This challenged their very identity as farmers, through its limiting effect on their ability to work:

“Yes, not being able to do nothing yeah, I’ve never had this in my life...never been off in my life, never missed a day’s work in my life....don’t think I’ve ever been in bed for a day in my life.....I find it very stressful I tell you that.” – Arthur

This was followed by a guarded return to health and slow return of existential wellbeing. However, most of the men perceived that a certain loss of body integrity remained; they spoke of having to remain vigilant and wary of over-exerting themselves on the farm, in a way not considered previously:

“I’m getting used to it but, I’ve got to, you know, because if I don’t... I can’t go to work 7 days a week like I used to, because I get so frustrated that I’m worried that I will be rushed off to hospital if I do.” – Colin

“I didn’t feel like I wanted to work 7 days a week any more, which I have done most of my life, so it was time to slow down.”
– Harry

SAP, then, was not a pain without consequence; the spectre of it remained, haunting these men’s everydayness. The fact they were diagnosed with ongoing heart disease meant they perceived their bodies were now not as reliable, able, or trusted. The illusion of indestructibility had faded:

“Not ... I go steadier, I’m not going flat out all the time, I have thought about saying, I, I, take it steady and get someone else to do it, if there’s lots of running to do I takes it, you get and run, I’m older than you, so that’s why erm, I just think about it more, you know why the bloody hell should I run after that, so...” – John

Most of the male participants actively looked to manage their life-styles more effectively, to limit further risk; this tended to be linked to work stress and “*the right sort of*” exercise:

“I am comfortable that I am still doing something, keep my brain active, um but also happier that I have got more time here and more time to myself than I had before so, you know it was for me in some ways it was a life changing situation um twelve months ago and uh I have now decided that I don’t need to put myself under that sort of pressure just to earn a bit more money, um, we have made compromises and we will just live on what we can earn.” – Kevin

However, for those that undertook lifestyle changes, the health practices linked to maintaining body stability were not without some perceived social pressure. According to Jacob, his commitment to self and body was at some odds with how farmers are perceived to act:

“I just know what I am doing now is right, umm, and these things you know it sounds simple but it’s walking through my local village, seeing the farmers coming down in their Land Rovers umm, I found it very difficult to start with and I thought gosh I should be working like them, blah blah blah, but this now of you know putting my hand up, I might stop for a chat and then someone says oh I can’t stop too long I know you’re walking and you don’t like stopping. They know why I’m doing it, um so very often they don’t stop now. I have gone through

that barrier of thinking oh god this is useless you shouldn't be walking you should be earning money.” – Jacob

Jacob found being viewed by other farmers, while out on his fitness walks, disconcerting, because he perceived they would think he was failing in his duties as farmer. However, he was reconciled to a corporeally-led sense of responsibility to his health, in order to maintain his farming life.

Those men who wished to pro-actively manage their health found that to do this they had to consciously demarcate between their role as farmer and angina sufferer. As we stood admiring his rolling fields, Jacob recounted how he had taken to doing his fitness walks away from the farm. I questioned this, amazed he would wish to walk anywhere else (as I thought his farm beautiful), but he confided that, when he walked through his own fields, all he saw was outstanding work to be done. This caused him anxiety. He did not enjoy the farm landscape in the same way as I, yet elsewhere he could watch the wildlife, enjoy the sunshine and just walk. Despite this, the men such as Jacob had realised through their brush with illness that their bodies were corporeal capital, in need of protection and attention to repair, if they hoped to continue to work as a farmer. That said, the farm still held a powerful symbolism for most of the men, revolving around its needs and their perceived duty to service those needs, before their own.

Alleviation of SAP allowed the men's lived space to lose some of its apprehension. The landscape they worked in became less vast and treacherous, as their movement through it improved, once more. There was one noticeable exception. Kevin lived on a particularly isolated farm and his concern about being trapped by bad winter weather remained prominent in his mind, throughout the study. He struggled to accept if this was rational or not, maybe looking to me (as a clinician) to assure him in some way:

“I suppose if I am honest I have got a deep seated fear of getting ill up here and being isolated, that is always at the back of my mind, what if, but on the other hand I don’t feel unwell, and there is no rational reason why I should think that.” – Kevin

After our last interview, he confided in a whisper that he now wanted to “*get off the hill*”, which I took to mean give up farming, possibly for the sake of his own health and wellbeing. This was set against most of the other men’s views. However, I suspect he whispered this because he felt his wife (and co-farmer) did not hold the same viewpoint.

7.5.1.5 Farmer body reaching out

As treatment availed itself and SAP was subdued, most male participants began to discuss future possibilities, more positively, and I sensed an increasing awareness of wellbeing permeating their third interviews:

“I seem to have coped with it all alright. I haven’t had too bad a year. I have come out the other end feeling better which, is a bonus, um...” – Harry

Ultimately, SAP forced all male participants to confront their health and most to communicate more openly about their concerns. A number of the men talked of how they felt changed in this respect and for the better. The frustrations and inner turmoil many endured at the start of the year had dissipated through successful treatment, but also by adopting a more open stance, particularly with partners:

“I think, erm, I am a lot better, more relaxed, don’t lose my temper so much, so quickly as I used to, erm, erm, I think I’m far better a person and talking to my wife before I wasn’t so, hyped up with the work and the problems.” – Jacob

Kevin also spoke colourfully about how his release from SAP had in some way left him more “*open-hearted*”. He described this as being both emotionally charged and more aware; his body and emotions no longer held in check, but now able to express himself more freely and reach out through them:

“... (5 secs.), erm, (5 secs.) ... now it might be because I’ve had a rash of funerals lately, in the last couple of months ... four and another one tomorrow in Hereford, a very sad one, erm, (5 secs.) ... I think I’m more emotional ... than I was, erm, I’ve never not been emotional but I’ve been, I’ve been tearful on many more occasions, erm ... yeah, now whether that’s to do with my heart because I-I have some beliefs about the function of the heart beyond physiology...”

“Well the fact that you know the heart feels like the centre of erm, a lot of emotional investment ... and, and joy as well and ... I certainly think if your heart in those terms isn’t open, if you’ve got blockages then I’m, I’m convinced that, that erm there’s an emotional element to heart disease.”

“... now with the heart, erm, a lot of last year, certainly 2010 ... I would have said my heart was not able to open a lot somehow ... and ...” – Kevin

This description of embodied release brought on by illness and then intervention was powerful. It also indicated Kevin’s decision to be more open regarding his own vulnerability. For him this seemed tied to a new sense of finitude, and realisation of its preciousness, and need to grasp life.

In less articulate ways, yet no less telling, a number of the men spoke about how their experiences had nurtured a deeper understanding in their relationship with their partner. They recognised the sacrifices partners had made and the effect their illness had upon them. Some

were surprised and yet reassured by their partners' commitment to them, over this period:

"Umm ... I guess it has in some ways but all its done is reinforce my feelings towards her in that she has supported me when I have needed it and I guess in the back of the mind you always wonder whether that would happen and it has, so it has been positive from that point of view." – Nigel

"Yeah, I think it has a lot, erm ... she erm, she was very attentive and very good towards me before but ... she's even better now! Erm, she erm, some things that crop up, she's 'Jacob mustn't go and get stressed about that', she'll help out, erm, whereas before you know it was oh you're better now, it was, no she cares a lot more for me now." – Jacob

"... It's brought us closer together but um, I don't know how you define being brought closer together..." – Don

When I pressed Don why he felt his illness had brought them closer together, he sat back and pondered my question for quite a while; eventually, he leaned forwards in his chair and replied, succinctly:

"Well it goes back fundamentally to, well basically loving one another really." – Don

Over the twelve months of the study, for most of the men, dealing with SAP brought them closer to their partners, after the initial uncertainty and fear linked to loss of freedom, dignity, resultant tacit trust in their lifeworld, and not knowing quite how to manage this. Unfortunately, such a positive endpoint was not shared by all the men. As already indicated, two couples separated during the fieldwork, the negative relational consequences of SAP apparently contributory to this.

7.5.2 The female partner: After their partner's illness

Although I refer to this as the second half of the study, in reality the couples' recovery from SAP was a staggered process. However, successful treatment did cause a demarcation, a clear before and after, where several of the women, rather than being relieved and ready to return to normality, reported that their experiences had left them still spiralling downwards, despite SAP's alleviation. It was clear that the existential suffering-wellbeing trajectories of these women did not mimic their partners', or run in tandem. In fact, for a number of the women, it lagged behind their husband's recovery, noticeably. Jacob made specific reference to his wife's deterioration, at the same time as he began to show improvement:

"I think you know through the erm, erm, the, the depression erm, with me coming out of hospital, erm, then it coincided with Linda going downhill, erm, there was erm, that awful time earlier in the year, when we were getting over it erm, but Linda then going downhill where I was getting better and better and better, Linda was going down, down and down." – Jacob

7.5.2.1 Partner body trauma

There was a crescendo, while their husbands were in hospital and initially after their return home. The women felt physically stretched to their limits. Duties on the farm, commitment to other work, visiting hospital, while trying to maintain control, created turmoil in their lifeworld, where habitual trust and conformity was tipped upside down. Corporeally, their lived body was in a spin; sleep a rare and brief commodity for some; support limited for most:

"Because he needed us up in the hospital so much, I never, never dreamt that he needed us every day to go up there ... that was a big strain that was, and the dark nights and, we had

to come back and do so much, and do so much before we went and had to get up early and I never...” – Molly

Significantly, the care their husbands received in hospital did not extend to the women. This left a number of them struggling under the weight of responsibility to their partner and the farm, yet feeling isolated, frightened, and ultimately trapped by circumstance. Jane painted a picture of this sense of hopelessness and frustration, being unable to obtain support and yet feeling guilty for needing it. Certainly, in Jane’s view, her needs as a carer were not recognised:

“I found that there was nowhere for me to go. Sounds silly don’t it? (Laughs). It sounds silly but I mean, don’t get me wrong I am not saying ... that I should take priority over the patient, do you know what I mean, obviously, a bad heart without your heart nothing else functions, do you know what I mean? I understand that. But it was if it all fell on my shoulders then, do you know what I mean? I had to keep myself together because if I fell apart the kids would fall apart ... and that couldn’t happen. Do you know what I mean? And it’s like if I fell to bits then it would make (name) worse because he could see that I wasn’t coping. And it’s like a big vicious circle, where all the doors are shut and you can’t, there is nowhere to go, and it’s frightening (laughs)... it’s frightening and it’s a lonely place as well to be.”
– Jane

A number of the other women spoke of feeling invisible during their visits to the hospital. They were often excluded from their partners’ consultations with doctors, and left floundering about how to support their spouse. In some cases, e.g. Janet, there was a suspicion that their men were complicit in this barring:

“... you are excluded and yet you are, but you are, you’re there aren’t you, erm ... how you get round that? No idea because of

time, the consultant can't have you in there, the patient wouldn't want you in there, but there is definitely a lack of, well maybe you could have a print out, you, you in lay-man's terms about the patient's condition that perhaps could be given to the wife ... but if the husband doesn't want you to have it, ptttt!" – Janet

Support remained piecemeal for the women, generally, as already highlighted in the previous sections. Again, some spoke of how they found our interviews supportive. This took me by surprise, particularly as I visited participants as researcher and not a clinician. My questions were open-ended and I offered those whom I was interviewing no advice in return, only time, space and a commitment to listen. Yet, a number of participants felt impelled to tell me that they had valued our meetings:

"You visit people in their own homes and people say its invaluable, its real grassroots stuff and even if you weren't in the study I would have thought there was a place for a cardiac nurse of any kind, or part of the team to actually visit and find out what's going on ... I think people are far more relaxed talking in their own environment and possibly they are far more likely to ring you and say I've got a problem, but in fact I think you take away the problems by entering their world by saying I understand how you are living and what you are doing." – Carol

As with their men, there was also a pervading concern that the doctors did not understand what farming involved, and therefore could not offer credible advice about managing heart disease within this occupation, safely:

"It never seemed to me that anybody really took into account his profession ... and I thought that was incredibly important for

them to understand, erm, yeah, and as they are all doctors they should understand.” – Janet

“I mean when he came back from one of the visits to Hereford Hospital and he said, they told me not to change my lifestyle. I said oh my word, they have no idea what your lifestyle is like, of course he does in three days what most people do in five and, I thought that’s the worst thing that could be said to him really, because you know he works from the minute he gets up in the morning until he goes to bed.” - Alison

The continued multiplicity of roles that many of the women faced, during their partners’ initial recovery after surgery or stents, put considerable strain upon them. An expectation that their spouses would be well again did not materialise, straight away, and so an on-going waiting game ensued.

During this initial post-diagnosis period, the past haunted a number of the women; it thrust upon them unpleasant comparisons with a healthier and, in some cases, happier self. For some their relationship with their husbands appeared stronger and more certain in the past. It was seen as a place where their younger selves played, with more energy, vitality and less worries to hinder their progress through life. For Christine, there was regret in the past that they had not done more as a couple; particularly now illness had invaded their lives:

“...it’s uncertain (the future), you know like I just think... (sighs)...er, yeah, it’s, for lots of reasons like, you know, I sort of think, you know like, there’s things we should have done...before that I think now maybe...” – Christine

A number of the women recognised how the past, its farming tradition and their men’s dedication to it, drove their spouse on, despite heart

disease, but also placed added pressure upon him, now that he had a potentially limiting illness. Dented pride and loss of identity were perceptively mentioned by some of the women:

“I think he’s fed up with himself, I think he’s just, he doesn’t want to, doesn’t want to talk about it because it hurts, he’s supposed to be a very strong, able man and he is but this erm, this is something that is happening to him, and I don’t think he finds it hard to do it, don’t think he finds it easy to deal with.” –

Brenda

“It must change his view of himself, yes it does, hmmm ...” –

Janet

“What he’s been born and bred into could end up killing him.” –

Jane

“Well inheriting a legacy and then having to live up to other people’s expectations and just the whole family dynamics of running a farm as your father did. Very hard for people, very hard for partners to come into that too, so...” – Carol

Such temporal waves reinforced the women’s sense of isolation, particularly the younger participants. These women did not have the same stability within the sea of uncertainty that experience and relational longevity appeared to give the older women. They tended to be more apprehensive about the future and expressed greater resentment for the change their husbands’ illness had brought and could bring. Where the older participants were able to reason that heart disease was part of the ageing process, to a certain extent, the younger women did not have this buoy to hang on to. Christine and Carol, with thirty years between them, highlight these differences:

“I think the main reason being, it was, it just, somebody relatively still young you know, and you sort of , like, I always think, well I don’t know, generally, it, I, yeah, we associate it with much older people, and then sort of thinking, oh my god, you know somebody so young really, with erm, with all these complications that you associate with much older people, you know you just sort of thing, it’s just, yeah, it just seems a bit unfair ...” – Christine

“I think it’s just a matter of coming to terms with ageing really and there is a sadness about that really, I suppose it is all linked into the idea of retiring and you know not being as able as we used to.” – Carol

There was indignation from Christine and resignation from Carol, with respects to where SAP suddenly appeared to place them, with their partner, upon the mortal coil of life.

7.5.2.2 Partner body diluted

Just as they distanced themselves from their own bodies, so the women found themselves distanced physically from their spouses, despite their increased need to care for them. For most of the couples, intimate relations were eroded by the need to care. A number of the women made reference to this, accepting the need to take on such a role, but expressing some anxiety about how this changed their relational dynamic:

“Well, I said to him, you know, not long ago, I said you know, I just feel like I’m just like your carer, you know, or your mother kind of thing ...” – Christine

Janet spoke earnestly about her difficulty balancing the various roles she was now expected to fulfil:

“... for you as a woman the extraordinary thing is that sometimes you feel like you are being their mother, in the morning, by the evening you’ve got to be the wife again, and be the whole sexual thing and that is quite a rollercoaster, so, erm, your head can get quite scrambled.” – Janet

This confusion related to role, duty and their own needs was deeply troubling for a number of the women. They missed their “former” partner, both emotionally and physically, particularly in the early stages of the disease. Alison, like a number of the women, lamented the sacrifice of sexual relations to illness:

“I don’t know whether it will come back for me really because of his condition, I don’t know. If it doesn’t it doesn’t, if it does fantastic, hmm, yeah, it’s not a big problem.” – Alison

Several reasons were given for this distancing, the main one being fear of further injury to their partner, as Alison alluded.

“How have we managed as a couple? Um, it’s not an easy one to answer that. I think emotionally we have coped quite well really. The physical side of our relationship disappeared because one was anxious as to whether you should or shouldn’t, so that vanished, um.” – Alison

Indeed, Kevin also recounted with some amusement, similar anxieties from his partner:

“... she did say once she was worried ... she worried that I might actually pass away (laughs) while we were making love, which I suppose is a very common thing if you have a cardiac husband, er, never occurred to me.” – Kevin

Although I did not question the women further than I felt they wished to go on this subject, I was sensitive to the sadness in their tone and facial expressions.

In the midst of a diluted relational stasis Jane spoke of a *“life lost”*:

“But he ... and this is going to sound awful, but the guy I met sixteen years ago is gone and he’s got health issues ...” – Jane

However, this perspective was not shared by most of the women. They hoped that their present relational circumstances were transitory, rather than a new way of life. Even during this period, it was not a case of “all or nothing” related to their inter-subjectivity. Janet provided a good example of the complex and sometimes contradictory stance dyads took. During her final interview, she admitted that illness had dampened her husband’s attractiveness and her wish to be sexually active with him:

“Yeah, er, yeah obviously when he was ill the sex side of things dwindled quite a lot, er ... probably because I, well I found it erm, it was a bit scary really but it would be, and erm, and then of course you know a man’s masculinity, you don’t, you are just not attracted so much, to somebody who seems to be ill, and he was ill, and he smelt different.” – Janet

Janet talked openly about this embodied sense of her partner’s weakness in illness. Although it nurtured a need to care for him and strengthened her love for him, she was rather put-off having sex. However, she did not feel that this had totally isolated her corporeally from her partner, or had affected their relationship, adversely. Indeed, she was able to articulate that intimacy between them had evolved, due to her spouse being more honest about his vulnerability:

“... apart from the, you know sex, the intimacy was, was erm, more developed, more sort of hugs and kisses and stuff, it was more, erm, and more, we were able to be more affectionate with each other...” – Janet

Janet and her partner both spoke of learning to share each other's vulnerabilities over the year of the study, and in doing so reflected that their ability to cope and trust each other had improved:

7.5.2.3 Partner body returned

As a disturbed normality returned, a number of the women felt their bodies re-emerge from their self-enforced *“invisibility”*; however, this did not mean that the body came back revived. Half the women suffered their own body disruption, intriguingly for two, they harboured their own fear of a possible heart problem:

“Erm, I had chest pain and I'd had it for quite a while, erm, and then it just wouldn't go away, I can't remember when it was, so, and it stayed there ...” – Brenda

“Oh I'm fine. I did have a bad time in the spring, umm, I couldn't, I was getting the most incredible pains in the evening, very high, in the top part of my chest so, and nothing would shift it and I couldn't get to sleep ...” – Janet

It is unclear whether these women were demonstrating an enactment of reflected pain, as experienced by their spouse, now transferred to them. Having concentrated upon and, in some cases, magnified the experiences of their men, through sympathy or inference, the women were now re-establishing their own needs, but finding their experiences were not without personal scars. They discussed this release, in terms

of a sudden bodily letting-go; like an elastic band recoiling, the body returning to its previous state, although now somewhat over-strained:

“Hmm, I don’t know probably a combination of things and erm, and you sort of I suppose it’s going through a crisis situation you sort of hold it together don’t you and then when you come out sort of, the other end, you sort of like collapse and yeah, so there’s probably an element of that really it’s erm ...” – Christine

“Once he had his stents done obviously he was better then, it was like this huge relief well now I can be ill.” – Janet

In their acknowledgement of the wounds inflicted upon them by circumstances, some of the women began to resent the previously familiar structure of their lifeworld. Suddenly, the home, a facet of selfhood, identity, and dyadic sharing was rejected. What had been a stronghold of emotional attachment felt suddenly foreign, emptied of anchoring familiarity, as Brenda and Jane recalled:

“Yes, I didn’t know where I wanted to be actually ... yes, I did, I did because I couldn’t feel anything for this place, for anything, but just nothing ... only people who had not given me hassle...”
– Brenda

“... it’s weird it is cos I don’t see the house as my home any more, it’s a house. Silly isn’t it? It’s just a house.” – Jane

This disruption to their perception of their “home”, what it held with regards to the present and hopes for the future appeared blunted by their spouses’ illness, for a number of the women. These women felt an increased sense of “disbelonging”, due to the disruption SAP had

caused. It had challenged their lifeworld, their relationship with their partner, ultimately, their tacit trust in the world.

Before the end of the study, two of the women left their partners, and the claustrophobic space that had replaced their homes. Blame for their relational rift was aimed at the men's disregard towards his own health, construed as also being reckless with their relationship:

"He will probably blatantly openly admit that to you, work came first, family came second ... But it's like I said to him what for? Why did you work 100 odd hours a week, why, what's it done, where's it got ya? I said bad health" – Jane

In her last comment, before the tape was switched off, Jane lamented that if the provision of healthcare had involved the needs of the whole family, then the consequences for her might have been different:

"... it would be nice for the kids to have something to put it in. I mean mine are getting older now so ... It would be too late for mine. I don't mean that selfishly or anything but if it stops the family going through what we have, it's worth it, honestly. And I know it all costs money and what not but, but this has ripped us apart ... What money do you put on keeping a family together? (Tearful)..." – Jane

Brenda in an attempt to salvage both her relationship and sense of place in the home looked to change her surroundings, as well as gain some acknowledgment from her husband that she was still relevant, visible and appreciated by him:

"... she (her sister) said 'Brenda why don't you use your old dining room set up sky in there, sky plus and have a settee and a chair, have your table for your work, and then sometimes if he's watching something you really don't want to watch, go into your room'. Now that's what we did, sometimes he's in there

and I'm sat watching the main one but we've got two sitting rooms now and that's worked really well, really well, and like also I take, if I do bring any work home, it's not in front of him, in the sitting room with my head in my laptop, it's actually in the other room ... and it separates it I think." – Brenda

When I asked what was best about this change, she replied:

"He's listened to me ... because I had begun to think that the man I saw over this year wouldn't listen to me anymore, but he has done." – Brenda

This poignant response highlights the important interplay between spatiality and other existential dimensions of the lifeworld. By changing her living space, Brenda became corporeally more at ease in her home and her relational ties to her husband were re-enforced by his actions to undertake these changes.

Only when their wounds and needs had been recognised, either by their partner and / or doctor, were these women able to find some stability, once more. It was as if this acceptance of their own stressors caused by their partners' illness needed validation, before they were able to move forwards and re-establish a sense of trust. Janet recalled, after a visit to her local GP with chest pain:

"When I came home all the symptoms had gone. It was just sitting down and having somebody taking me seriously, listening to me, giving me some pills (laughs) dotting the system, you know, having blood taken, so it was a placebo in the same way." – Janet

This woman's body reappeared in the calm after the storm and she was able to re-orientate herself again, corporeally.

Towards the end of the year of the study, most of the women felt that a sense of body equilibrium had returned – an inter-subjective sense of belonging, once more. However, a tension remained, related to their perceived and continued need to covertly observe their partners' activity levels, while at the same time suppressing on-going anxiety related to this:

"I mean you know I keep, I suppose a quiet eye without realising that I am doing that and without him realising, but it's important that he doesn't realise because otherwise he gets cross because he thinks I am watching him all the time you see, so I have to just kind of detach myself a bit from it." – Alison

A number of the women spoke of a sense of reconciliation with their partners. It moved one couple who had cohabitated for many years to marry. For others, it was the satisfaction of making time to talk to one another, more openly. There was a return to sharing and trust. It was a union made stronger by illness in some couples, as Brenda confided:

"I love him and I always have done and I lost sight of it I think and perhaps he lost sight of it too because we'd just had an awful lot to do with erm, so we're both, you know working to get that back again." - Brenda

Janet spoke of the importance of being able to share each other's vulnerability, which, in doing so, had strengthened their relationship:

"... because of his vulnerability, he was easier to love ... it's not very easy to love somebody whose raging round the place being angry, grumpy and depressed, and over-tired and all sorts of things so it was, yeah, it was that his vulnerability and his, niceness if you like and his ability to empathise a bit more it brought that side out of him..." – Janet

The shadow of SAP had not fully lifted for the women. Caution remained a constant in their lives, one year after initial diagnosis, and occasionally for those such as Carol, the trauma of their experience rose up bodily, in unguarded moments:

"It's only occasionally I dip back into the, it's not a real terror, it's just a place where I can go where I just feel well I have just got to wait and see. You know life is ever short. You know, any of us can become ill at any time. So I suppose I have become more conscious of that." – Carol

In the same way as some of the men, a number of the older women spoke of their own mortality, following this brush with serious illness:

"I suppose accepting, yes really, it has certainly faced us with mortality and the fact that you don't go on forever, um, I mean I think that would have been far more dramatic that sense of um, mortality if he had actually had a heart attack, you know and I knew he was almost at death's door. I mean the strange thing about this still is that it was just angina and that it um, it is unprecedented all this sort of dramatic response really which I still find a little distressing really... difficult to understand." – Carol

"I don't know, grinds you a bit doesn't it, you know, you suddenly think oops, yes this is me, now in the next pen so to speak." – Alison

Alison's analogy of being in the next pen (in farming terms) is synonymous with the movement of sheep in an abattoir, towards the last pen before death. Despite this sober assessment, there was also a sense of optimism, shared during many of the final interviews with participants. Even for Janet, one of the few active female farmers, there

was recognition that their relational integrity took precedence over any commitment to the farm:

"I think the future's quite bright, we are in a very lucky position, Kevin can do less work, erm, he can always go and pick up bits of work, we live in a place, which seemingly looks difficult, it has a lot going for it, we are very independent, erm, apart from the steep track in the winter, I'm sure we can, and we are both able to think our way out of problems, and if it becomes too difficult to live here then we'll have to move somewhere it isn't too difficult really, so I, the future is very bright." – Janet

7.6 Reflection Two: Beyond Love

"But we want to delude ourselves that love is the root. It isn't. It is only the branches. The root is beyond love, a naked kind of isolation, an isolated me, that does not meet and mingle and never can ... It is true what I say; there is a beyond, in you, in me, which is further than love, beyond the scope, as stars are beyond the scope of vision, some of them."

- D.H. Lawrence, from *Women in Love* (1920)

The year 2011 was eventful for all the couples, experiencing the instability to lifeworld caused by SAP, set against the demands of a farming way of life. As I approached the end of field-work, I hoped Moustakas's view about love being lost by illness (and which I reflected upon at the start of this chapter) would be proven wrong. For my participants, I wanted to be able to evidence that love was the driving force that kept them going and ultimately able to face their crises together. There is plenty of evidence which suggests dyadic coping is superior to an individual facing illness (Berg and Upchurch, 2007; Wood

et al., 2008; Walker and Luszcz, 2009). I would celebrate this, recording at the same time how I, through considered analysis, was able to disagree with the great man. Hope for us all, then!

In his follow-up book to *Loneliness*, aptly titled *The Touch of Loneliness*, Moustakas (1975, 104) talks about love, again, and quotes D.H. Lawrence to outline his argument, which I used to open this section. Here, Moustakas (1975, 105) contends that love is not the answer, when a person becomes isolated by personal crisis; it is the “*being alone*” to consider self that is the solution, in which “*a new truth arises that enables a person to return to life with others*”. I recognised that, at the end of 2011, I had sensed this movement within the dyads, the corporeal and relational distance between couples transiently further apart, each taking their own path to deal with what SAP meant for them; each, eventually, having to attend to the imbalance within their own existential lifeworlds, before being able to contemplate the other, again. For some, this meant going it alone, love broken (by illness maybe) leading to separation; whilst for others, it brought recognition of a deeper bond, of love strengthened by the trials of illness and shared vulnerabilities. Two of the couples separated and one dyad married, after many years’ just cohabitating, during the turmoil of their year. Sadly, too, a few months after final interviews, one of the men died of a heart attack, while out on his farm. This sad news brought home to me the fact that heart disease did not end when I finished the fieldwork; it was on-going for participants. His death came as a shock; in a small way, all the participants had become part of my world and I cared about their welfare. In this respect, I found myself agreeing with Moustakas’s (1975, 18) reflection that he had:

“gone ‘wide open’, ceasing to be a separate individual, but wholly related to the other person, leaving something behind of my own intuitive vision, and comprehension while, at the same time, taking something away”.

I now concede that Moustakas was not wrong in his assertion that love might be lost, during illness. Yet, I am not deflated by this; rather, I am reassured that I have looked a little deeper and now understand a little better. Theirs was not only a physical journey, but an existential one of self-discovery, the living through and the learning from illness, all part of the path each participant had to tread alone, for a while, until existential trust in the world could be restored. Galvin and Todres (2013) argue that wellbeing is reconciled from deep within our embodied being, that *“people find their own unique way towards wellbeing”* (Galvin and Todres, 2013, 77), through a tacit knowing linked to one’s own lifeworld and limitations of life. The evidence of this study supports this claim. At the end of Loneliness, Moustakas (1961, 103) concludes:

“Being lonely and being related are dimensions of an organic whole, both necessary to the growth of the individuality and the deepening value and enrichment of friendship. Let there be loneliness, for where there is loneliness, there is also love, and where there is suffering there is also joy.”

Movement towards self and back to world, in order to try and gain some footing in the unfamiliar landscape of illness, like uncertain dance steps before balance and co-ordination are achieved, is best first practised alone, it would seem. However, we are never really *“alone”* and inter-bodily resonance, memory and mutual perception (Froese and Fuchs, 2012) are implicit in a couple’s history, whether they like it or not; all set against a cultural rhythm they strive to maintain. Flannagan’s (2013) quote at the start of my thesis describes this beautifully. Here, therefore, in their unintentional intercorporeality and guarded attempts to cope with illness alone, the problem might lie.

7.7 Summary of the Chapter

This chapter has taken the reader on a descriptive journey through the lifeworld experiences of eight Herefordshire farmers with SAP and their

female partners, over one year. Three time periods are highlighted: the development of chest pain; living with SAP and recovery after SAP, as these were the temporal points around which important themes wound themselves.

The next chapter discusses these findings, and offers interpretations, related to the participant groups (men versus women), differing existential suffering-wellbeing trajectories, dyadic coping and the progressive erosion of existential trust. Consideration of how healthcare was contributory to dyads existential suffering with SAP is also undertaken.

Chapter Eight: DISCUSSION, PART ONE: MAIN FINDINGS

“the farmers market
friends offer condolence, I
sell reassurance”



*“I got sick of everybody asking me how he is really; they very rarely ask
you how you are (laughs)... I think most carers find it.”*

Mary

8. Chapter Eight: DISCUSSION, PART ONE: MAIN FINDINGS

8.1 Introduction

In this chapter I present the main findings of the Farm Angina Project. From my interpretive analysis of the longitudinal data I contemplate temporal themes related to the suffering-wellbeing trajectories of both participant groups (male SAP sufferer and female partner); the relational impact of SAP and how this contributed to an erosion of existential trust for all, which pervaded expressions related to their lifeworld. Finally, how healthcare, in not acknowledging participants lifeworld needs, was complicit in the existential suffering they endured individually, and as a dyad.

8.2 Main Findings

This longitudinal hermeneutic phenomenological study revealed the following phenomenon:

The existential lifeworld's of both members of a farming dyad were disrupted by the introduction of illness in the male partner. However, each spouse experienced SAP existentially differently, as evidenced by their suffering-wellbeing trajectories. Couples practised bodily subterfuge, in order to manage vulnerabilities inconsistent with their worldview. The men with SAP attempted to hide body disruption, to maintain their sense of self and social standing. The women became body invisible, to conform to dutiful care-giving, supplement their partner's farm-work, and distance themselves, inter-corporeally. Disharmony between body, self and world, during illness, also eroded the participants' sense of existential trust. This was inevitably contributory to the way dyads coped.

SAP caused both members of farming dyads corporeal and inter-corporeal uncertainty. The men initially endured corporeal disruption in their lifeworld due to the bodily limitations SAP put upon them. Over time, the threat to freedom this brought began to challenge their sense of self-identity and how they viewed the world. Female partners also endured corporeal instability related to their spouse's illness, through an emerging inter-bodily incongruence between them. This became existential suffering predominantly within their inter-subjective lifeworld dimension. These perspectives appeared influenced by cultural factors, closely allied to a patriarchal family farming lifestyle; and proved particularly detrimental for female participants not directly involved or from a farming background. Each trajectory was influential upon the other, and appeared to shape how dyads coped with SAP.

Both partners suffered an erosion of existential trust, due to the disruption in their respective lifeworld's that illness and the perceived, potential loss of freedom wrought. In order to protect their vulnerability, dyads practised a degree of subterfuge to maintain a sense of self-control in the early stages of the male's illness. The men tended to hide physical symptoms from partners; the women practised a degree of corporeal disregard / denial in order to cope with the demands placed upon them by their spouse's illness. Again, socio-cultural factors related to their farming way of life appeared to influence these relational patterns. This caused steady erosion in self and dyadic relational trust; which also affected their tacit trust in the world, alienating them, to a certain degree, from all that usually seemed so familiar. This new orientation repeatedly coloured their existential mood, which further affected outlook and actions.

Healthcare practices did not acknowledge individual participants' lifeworld needs related to SAP; in some cases, dehumanising care was contributory to dyads' continued existential suffering. Aspects of the medical treatment regimen employed added to the existential suffering caused by SAP, for the men, e.g. feeling territorialised by their

medication, which affected their ability to farm; experiencing objectification and powerlessness, while in hospital, etc. Whilst this appeared unintentional, it was nevertheless impactful. Limited access to care services, such as their local GP, also felt restrictive and unwelcoming to participants. This led to the men experiencing a loss of experiential and relational dignity and trust. The healthcare received also had an existentially negative impact upon most of the female partners. A number of reasons were discussed, but primarily it was due to partners being omitted from their spouse's care; this also included feeling ignored by doctors, and receiving conflicting and incongruent information, when attempting to understand SAP, from a biomedical perspective. This led to strain for many of the women, trying to uphold a caring role, with no obvious support or acknowledgement, whilst also trying to come to terms with their own disrupted lifeworld.

This study offers a unique, temporal view of farming dyads' experiences of SAP, divided in to three time periods over twelve months. It highlights similar stages as discussed by Miklaucich (1998) whose paper I reviewed in chapter three; particularly going from "*fearful living*" to "*accepted limitations*" caused by SAP. However the experiences recorded in my study also extended beyond those of Miklaucich (1998). The intervening years have seen the advent of new cardiac medication and interventions, such as PCI, which have improved clinical outcomes. Therefore my study was able to avail the experiences of SAP sufferers after successful treatment. This is a new experiential perspective which was not readily available to earlier phenomenological studies.

In some ways, my findings could be construed as an example of transition. The concept of transition within illness is a recognised phenomenon, defined as "*an unstable passage between two more stable periods; a time span with an endpoint, a period of instability and confusion, and an ending with a new beginning of stability*" (Fex et al., 2011, 253-254). The importance of understanding transition during illness has also been recognised as a pre-requisite of more targeted and nuanced healthcare (Fex et al., 2011). The Farm Angina Project

used transitional stages in participants' journeys to evidence their changing experiences, i.e. from initial chest pain, to a diagnosis of SAP, and eventually (for certain participants) its successful amelioration. However, I was aware, despite this representation, that participant narratives did not all speak of progression from one steady state to another. Often, there was back-tracking and further, differing instability, (e.g. due to diagnosis, medical interventions, lack of follow-up support, etc.). I contend, therefore, that the notion of transition does not fit easily with this study's hermeneutic phenomenological perspective and multi-layered findings. However, there is a danger that, in any summary of data, a false sense of transition between stable points may be given; this is not my intention. The next section reviews the differing suffering-wellbeing journeys of the men and women in this study and is representational of two common patterns. Again I must caution that these were not the only trajectories observed, only the most prevalent to emerge from my analysis of the data.

I will now discuss the interrelated facets of the phenomenon revealed by this study in more detail.

8.3 The Differing Suffering-wellbeing Trajectories of Farming Dyads

By undertaking a longitudinal approach, I was able to obtain more than a "snapshot" of the participants' lives; instead, a multi-dimensional and temporal understanding of their experiences emerged. By comparing key data from participant narratives with the existential wellbeing work of Galvin and Todres (2013), two commonly shared suffering-wellbeing trajectories were identified from participants within the male and female groups.

Galvin and Todres (2013) argue that wellbeing and suffering are always in relation to one another, stating that care needs to consider both; it should comprise of a direction for care, based on wellbeing and a capacity to care, based on suffering; *"It is important to meet people in both their vulnerabilities as well as their possible freedoms; suffering*

announces vulnerability, and wellbeing announces freedom” (Galvin and Todres, 2013; 98). The importance of this view of care resonated with me, particularly related to my research. Over time, I reasoned that this approach had a place, both in my interpretation of longitudinal data, but also in my subsequent consideration of rehabilitation. Nevertheless, attempts to identify patterns within my data, using the authors wellbeing-suffering categories (see Appendix L), were not without difficulty. Narratives offered me “*shades of grey*”, rather than the stark “*black and white*” of specific dimensions. Eventually I reasoned, from my findings, that wellbeing-suffering dimensions may exist simultaneously within an individual e.g. suffering “*bodily discomfort and pain*” (located in embodied dwelling) as well as sense of being spatially “*imprisoned*” (located in spatiality mobility).

By comparing findings from farmers’ narratives with the work of Galvin and Todres (2013), two commonly shared suffering-wellbeing trajectories were identified within the male and female groups. For the men, these were situated within “*corporeal*” and “*identity*” suffering-wellbeing dimensions. Again, two commonly shared and intertwined suffering-wellbeing trajectories were identified in the female group. However, the women undertook different existential journeys from their spouses, enduring “*corporeal*” suffering, but differently from the men (which I will describe in the next section); this was linked to “*inter-subjective*” suffering related to their SAP partner.

8.3.1 The “Hidden”: The male farmer’s existential suffering-wellbeing journey

SAP caused a steady “*fragmentation*” to the men’s sense of self-identity, starting with chest pain and a body suddenly visible and out-of-step with the everyday flow of their farming lifeworld. As their vitality became increasingly depleted, so the body became more alien, turning what was a familiar landscape into unknown territory, warping time, and ultimately eroding their trust in the world about them. Movement on the

farm and temporal rhythm became stalled, their sense of being-at-home to dwell securely suddenly diluted and less solid. There was a steady but “*painful closing down*” (Galvin and Todres, 2013, 114) of corporeal dwelling and mobility wellbeing.

Diagnosis only brought further instability related to identity. It caused the men to fear the impotency that heart disease might bring – being unable to farm, which, for most, was their purpose in life; some viewed it as an insipid uselessness which could make them worthless. This was not assuaged by the medical regimen offered to manage SAP. During the early days of tests and hospital admissions, the men spoke of feeling objectified and powerless. The world and language of medicine caused some of them confusion and feelings of being divided in themselves, “*body as lived*” versus “*biological body*”. The drugs prescribed left a number of the men feeling territorialised by troubling side-effects and unable to be productive on the farm. Their healthcare providers appeared unable to grasp the existential suffering SAP caused these men, or the medical regimen imposed upon them, in some cases. Galvin and Todres (2013, 111) call this state: “*dwelling and mobility suffering in the identity dimension*”, describing it thus: “*fragmented identity is essentially constituted by the deep existential character of having succumbed to overwhelming objectifying forces that also make one powerless*”. The male participants provided evidence of a spectrum of suffering-wellbeing, along this particular dimension.

The men felt vulnerable and exposed and this led to erosion in their tacit trust in the world which, until illness, had held them in balance within it. Their sense of self, shaped by personal history and ingrained by their farming culture, was being challenged. In order to protect themselves and maintain what they perceived as their public persona, the men sought to conceal symptoms, as well as the fear and anguish that SAP caused. Significantly, their unique bodily being-in-the-world (involving movement, gesture, and more) confessed their subterfuge and plight to those intercorporeally closest to them, their partners. This created relational tensions of varying degrees for all couples within the

study. Sometimes the men's frustrations manifest as low mood or aggressive outbursts towards their partner, to which I will return.

During the twelve months of the field-work, a number of the men were successfully treated for SAP, i.e. their chest pain was eased by the medical regimen adopted and / or interventions performed (CABG or angioplasty and stents). This gave them renewed hope and inroads towards a state of trust returned; a balance between mobility and dwelling in their world, a state of wellbeing described as "*grounded vibrancy*" by Galvin and Todres (2013). The men were able to perceive their bodies as being able to go forth, once more, and merge with the temporal flow of the farm. At the same time, a sense of rooted belonging was re-established, to the land, its history and temporal synergy. Galvin and Todres (2013, 96) suggest: "*wellbeing as a sense of grounded vibrancy is any bodily experience where variations of rest and comfort are intertwined with variations of alertness and vitality*". In being returned to the farm, the men re-established ecstatic temporality and a vibrant sense of self. Importantly, however, not all the men were freed from SAP symptoms. For these men, an adapted freedom was carved out from illness, so that existential wellbeing and trust, despite ill health, could be maintained.

8.3.2 The "Invisible": The female partner's existential suffering-wellbeing journey

The women first experienced a corporeal sense of existential disruption, emanating from their spouse. A strange distancing emerged between them, which the women did not understand, that also led to rising and pervasive tension within their usually assured sense of dwelling. This was different to the corporeal suffering of their partner, born out their inter-bodily relationship, rather than an immediately experiential bodily change due to SAP; however, it was no less impactful. Over time, their spouse's illness was revealed and with this came a sudden destabilising in the everydayness of their lifeworld. This led to suffering,

most commonly within their “*inter-subjectivity, dwelling suffering dimension*”, defined by Galvin and Todres (2013, 104) as a rupture in one’s sense of interpersonal belonging and kinship.

The men’s reluctance to speak about their illness, mask symptoms (and yet be troubled by it related to mood and behaviour) created division and loss of intercorporeal warmth and belonging, which led to an erosion of relational trust, for several of the women. This added to their increasing sense of existential loneliness and vulnerability. At the same time, once the men were no longer able to hide illness, an unspoken dyadic expectation to support them and the farm created more inter-subjective suffering, in lieu of any other support for either dyad member.

Outside of this dyadic “cocoon”, the medical care the men received did not extend to supporting the women and, in some cases, added to their sense of existential suffering, e.g. being ignored on the ward and left in clinic waiting rooms, all added to their uncertainty and a sense of not being trusted for some reason. This lack of inclusion felt contradictory to their expectations, as carer. Lack of acknowledgement for their commitment to their spouse, created a growing sense of opacity. Support from others in the community was piecemeal, other female family members, particularly sisters, appeared their closest confidantes; however, the focus of everyone else remained upon their spouse.

The women became corporeally invisible, possibly through a culmination of lack of self-reflection in others and their own body denial, in order to maintain the many roles and duties they now had to fulfil. As with the men, the women’s existential suffering was layered and fluid, as dimensions morphed. Their corporeal uncertainty led to dwelling inter-subjective suffering. For some, such as Jane, there was also a noticeable shift towards spatial suffering, in which her home became prison-like, locked in by fears of her husband’s demise (see page 227). This slowly drained her home of personal comfort and belonging. Jane, along with a number of the other women, found that the tacit trust upon which her familiar world stood, was now made porous and brittle by

SAP, leaving her in alienated isolation. Jane became fearful that all she relied on to give her life meaning, might come crashing down, at any moment. As time went by, the women learnt the steps required to try and maintain balance in *“the dance of angina”*. However, this remained a conscious and measured intention, which was not always in step with their partner.

Eventually, towards the end of the twelve months’ study, the women began to recognise improvement in their men. Their inter-bodily knowing sensed a return of his vitality and spontaneity. Most of the men’s mood also lifted, as they became corporeally less restricted by SAP. However, a number of the women did not unite in their partner’s ascendance. Instead, they allowed their corporeal cloak of invisibility to slip and in doing so began to tend to their own wounds. This was done in full view of their spouse, now he was returned to health of sorts. A number of the women demonstrated corporeal suffering characterised by *“exhaustion and stasis”* allied to embodied mobility suffering. For some of the women, a commitment to dyadic *“belonging”* had to be made by her partner, before they too could accomplish some return to wellbeing. This may be linked with their suffering being primarily in the inter-subjective dimension. A return to intersubjective dwelling wellbeing is described by Galvin and Todres (2013, 86) as *“a sense of kinship and belonging”*. In this case *“a person feels at home with another or others. This sense of familiar connection constitutes relaxed situations of meetings in ways that can make us feel that we belong there”*. This can involve a reconnecting of people who share a history with one another but who may have lost a sense of closeness. As the authors suggest there is *“a sense of we rather than I or you; an effortless being together with one another, a sense of family security and togetherness”* (Galvin and Todres, 2013; 87). A number of things contributed to the women’s improvement in existential inter-subjective wellbeing. These included increased confidence in their partner’s health, along with his improved mood; a more stable inter-bodily and corporeal state; improved joint coping and communication; a perception

of the farm as suddenly less threatening and finally the return of a sense of future prosperity together. Dyads being able to sharing their vulnerability appeared integral to this; whereby intimacy and relational trust could flourish once more.

8.3.3 Consideration of dyadic suffering-wellbeing journeys

Other studies have shown that couples can suffer differing wellbeing experiences, following shared illness crises (Saflund and Wredling, 2006). Utilising the descriptive phenomenological method, Whitsitt (2009), found in couples experiencing CABG surgery that partners “*underwent a psychological process uniquely different from individual patients*”, but that they, too, suffer from the illness their spouse endures. This is in keeping with the findings of my study. Bodenmann et al. (2006) in their investigation of dyadic coping also reported that, for women, both their own dyadic coping and that of their partners was significant, whereas for the men, only their own dyadic coping appeared significant. According to Knudson-Martin and Huenergardt (2010, 375): “*an unintended legacy continues to shape heterosexual couple interaction such that women are more likely to orient toward relationship maintenance and men towards autonomy*”, arguing that this causes “*an imbalance in influence*” between partners (Knudson-Martin and Huenergardt, 2010, 376). Such “*unequal power positions and stereotypic gender socialisation can make the vulnerability inherent in intimacy difficult*” (Knudson-Martin and Huenergardt, 2010, 376).

The patterns of suffering-wellbeing evidenced in the Farm Angina Project were indicative of an autonomous male and relational female, although this could be skewed by the fact that all the men had SAP. However, Price and Evans (2005) also argue that female farm identities exist in a predominantly relational way to men as the primary farmer. A tendency to conceal vulnerability, as exhibited by both partners, may also be linked to culturally derived gender roles (Burton, 2004). I consider that there were elements within narratives to suggest that a

gendered power balance towards a patriarchal family farming lifestyle existed in most dyads, albeit in a stage of transition, due to the woman's more liberated, modern lifestyle. I also assert that this appeared to cause distress in both spouses, when the male became ill. Neither dyad member appeared to relish contemplating either the "*sick role*" or "*carer role*" associated with the arrival of heart disease, because they challenged both partners existing freedoms. However, those women more closely allied to farming (as co-farmer / housewife) appeared more at ease with their extended carer role and farm duties, as these were already culturally associated with their role (Price and Evans, 2009).

Almost all the participants regained some sense of wellbeing; for the men, this was commonly tied to improvement in their SAP symptoms. However, not all male participants benefitted from such intervention, such as George; yet, corporeal suffering to wellbeing was still observed in these participants, to a degree. Here, I evidenced that individuals drew upon inherent, embodied resilience to renegotiate how they could maintain a satisfying farming identity, despite illness.

Importantly, there was evidence of a lag in the return to existential wellbeing of a number of female partners, compared to their spouses, after his successful treatment, as mentioned earlier. Again, this was observed most prominently in their embodied and inter-subjective suffering-wellbeing dimensions. It appeared that couples' differing illness representations and the perceived risk farming posed were partly responsible for this staggered recovery. The women remained fearful for their men's welfare on the farm, even after successful treatment and this perpetuated their own existential suffering, to a certain extent. I also sensed there was something more. The women seemed wounded and angry by the impositions placed upon them by their partner's SAP, his response to it, and the degree of "*invisibility*" they had endured. Several women demonstrated this loss (possibly of trust) by rejecting previously cherished dimensions of their lifeworld, such as their home and / or relationship with their partner. During this period, these women

appeared to need recognition of their commitment and suffering from partners, as well as a demonstration of reciprocity (e.g. Brenda had her spouse change the carpets), before a return to wellbeing was possible. The women quite literally needed to be seen, not as an object, but as a sentient being with individual needs. Interestingly, these findings echo those of Erlingsson et al. (2012), who discuss how caregivers often slide sideways into such roles, following a sudden change in circumstance. From there, they move along a path of “*caregiving in reciprocity*” or “*caregiving in disintegration*”. In the first example, caregiving is participatory between the person being cared for and the carer, which leads the latter to feel they have influence, are supported, acknowledged and respected in this role, thus maintaining their sense of wellbeing. In the second category, caregiving is not participatory; often, the caregiver experiences isolation in this role and does not feel valued in its pursuit. Here, according to Erlingsson et al., (2012) wellbeing becomes suffering and also illness. Each of these caregiving paths could be seen in the Farm Angina Project, although they were not always juxtaposed or static, as inferred by Erlingsson et al. (2012). Indeed, Brenda was a clear example of a woman who experienced a certain amount of disintegration, at the start of the year, but who gained supportive reciprocity, towards the end.

Each participant’s experiential journey was a reflection of complex and shifting perspectives, brought forth from their lifeworld. Although I anchored my viewpoint to their corporeal experiences, this was not the only emphasis from their horizons of intentionality. Temporal and spatial suffering dimensions featured too and sometimes featured prominently in their foreground of experiences, as already alluded to. Differing states of wellbeing and suffering also morphed into each other, at different times and, on occasions, appeared to co-exist.

It is important to note here that existential wellbeing and suffering comparisons offered between male and female participant groups should not be seen as deterministic or conclude that they are based on the progress of the participant’s illness, alone. Such states are, by their

nature, unpredictable and “*spontaneous in unexpected ways*”; certainly, they are not just steered by health (Galvin and Todres, 2013, 96). Therefore, I am unable to discern accurately why these patterns emerged – only that illness was contributory to a destabilisation in their lifeworld. However, alongside any transition linked to their SAP, depending on the severity of their illness, other factors probably were contributory. Particularly those linked to the non-medical, socio-cultural domains of farming distress as discussed by Price and Evans (2009), such as the pressure to maintain a profitable farm in an adverse macro-economic climate; maintaining farm identities and roles; as well as the pressure placed upon farmers by the historically symbolic importance of their properties. I will return to these considerations later in this chapter.

8.3.4 Farming dyad intercorporeality

Participants corporeal as well as intercorporeal experiences were integral to the suffering-wellbeing trajectories evidenced, and so worthy of further consideration. The intercorporeality of all the farming dyads in this study were altered by SAP, as the pre-reflexive inter-bodily resonance between the sufferer and their partner became disturbed. As Trigg (2013, 413) concludes: “*body, other and world are each intertwined in a single unity and cannot be considered apart*”. Dyadic relationships have their own kinaesthetic inter-subjectivity, a non-verbally attuning movement and spatial orientation towards each other, which creates an existential stability upon which their conjoined lives are lived. Diprose (2008, cited in Zeiler 2013, 73) suggests we pre-reflectively share bodily gestures and postures through repetition and temporal proximity, which can become a part of the other’s “*corporeal style*”. Fuchs and Jaegher (2009) refer to this as “*mutual incorporation*”, in which two bodies share sense-making and rituals of incorporation.

In attempting to conceal symptoms, the men were unable to prevent eddies of change in their inter-bodily being, as bodily perceived by their partners; this brought a growing sense of uncertainty to their corporeal world, with a change in their self-other relatedness. Likewise, the women, in attempting to become invisible, could only manage this opaqueness, transiently, and returned wounded by the attempt.

During the early stages of the study, I evidenced that the couples became body-hesitant towards each other, as inter-bodily resonance was altered by SAP. For the men, this was linked to the objectifying effect of their illness and the subterfuge they employed to conceal body vulnerability. Unfortunately a couple of the men found that they became behaviourally more hostile in their defence of themselves. Other studies have linked poorly-controlled anger-hostility with the exacerbation of SAP (Gabbay et al., 1996; Gullette et al., 1997). Thomas (2003) found in a study of men's anger that they became so, when they were unable to "fix" their situation; with regards to SAP this may have been a factor. Denzin (1984) argues that men will use hostile behaviour in the home, to regain hegemonic status and the respect of other family members. For the women, there was fear that body contact might risk their spouse further injury. The increased hostility a couple of the men demonstrated also made their spouse's wary of closeness. Denzin (1984, 493) explains that such hostility can cause "*a distortion of the selves of family members, who become less able to consider the emotional attitude or understand the actions of the other*".

It also involved feeling less attracted physically to their ill husband (in Janet's case). A number of the men and women also spoke of feeling corporeally ill at ease in their partner's presence; through a fear of loss of self-control which may lead them to reveal their vulnerability (e.g. such as Colin). The women, more than the men, conceded that they appeared to touch each other less in illness, and lamented more readily their sadness at decreased sexual contact with their partner. This reminded me of the words of Sundler et al. (2009, 376) and made me

ponder how diluting such intercorporeal hesitancy must be upon participants' view of body and self-worth:

“Sexuality is something emotional that involves feelings of self-esteem, dignity, pleasure, and desire. It needs to be understood as existential and fundamental to human life; it encompasses our bodily being in the world as well as in our relationships with others”.

Arenhall et al.'s (2010) sensitive review of women's intimate relations with a partner who had suffered a heart attack found that the female participants suffered an acute sense of loss of their former life:

“Women experienced limitations on their life as a result of their partner's changed behaviour, attitudes and temperament. They were compelled to adjust to their partner's lack of sexual desire or function. The deficits and feelings of loss that women experienced culminated in a sense of life lost”. (Arenhall et al., 2010, 1683).

It is argued that touch is a foundational form of intercorporeal intimacy (and not merely in a sexual way) that “*undergirds*” the inter-subjective stability of couples (Maclaren, 2014, 95). Intimacy is defined as a sense of closeness, which matters in an interpersonal way (Maclaren 2014). Intimacy, however, is not just about body contact, but rather an integral ingredient of inter-subjectivity. The intercorporeal intimacy of farming dyads appeared affected by SAP and thus, their inter-subjectivity.

Alongside this erosion of intimacy came a defensive distancing in some dyads. Jaremka et al. (2011, 264) argue that:

“Defensively distancing in response to threat may help people with low self-esteem achieve their short-term goal of self-protection, but it has negative long-term consequences for their relationship”.

For a number of the women, this became a preoccupying state of uncertainty, again fed by a number of the men's increasingly aggressive behaviour in the first stages of illness. Although physically close to their husbands (in measured proximity), a number of the women felt spatially removed and isolated. The person they shared a joint world with, part of

themselves, SAP somehow divided, and with it he was suddenly an independent, uncontrollable “*other*”, with the power to destabilise her lifeworld. This dichotomy of the near and the far in their relationship unsettled several of the women, affecting their spatiality of entwinement, part of their embodied being.

Maclaren (2014) contends that intimacy is also linked to the establishment of shared values and concerns, over time, and within daily living. SAP appeared to close off the openness to the “*other*”, integral to such situational intimacy. The reluctance of the men to heed health behaviour advice, if it challenged their sense of self and the fear and resentment that this caused a number of the women, created a shift in orientation within their conjoint worlds. This led to a decrease in relational trust which, again, eroded participants’ tacit trust in their world, at once both familiar and yet now alien.

The men’s illness encroached upon the women’s sense of self, their own ecstatic temporality and being-in-the-world. Erosion of intimate relations with their now ill partner foreclosed the women’s own futurity, drawing them back into a socio-culturally derived sense of duty. This was suffocating for some of the women; because it was regarded as a role they had outgrown or did not understand, particularly for those who worked off the farm.

Fergus (2011), in her paper on the effects of prostate cancer in couples, talks of them possessing a “*communal body*” in which dyads participate in a shared corporeality, in order to come to terms with and manage cancer. I suggest that although intercorporeality was a powerful mediator for mood and action, it did not conjoin in the management of SAP, in the same way as reported by Fergus (2011). One might argue that the Farm Angina Project participants were self-seeking, the men in their reluctance to conform to anything other than their culturally given farming self, and the women in their struggle to adhere to new roles forced upon them by their partners’ illness.

However, I assert that their demeanour was due to an erosion of existential trust, pervading as a mood, the whole of their lifeworld. This created vulnerability that both the men and women found difficult to concede to the other. Only when the men became more open about their body vulnerability was there some return to relational intimacy, as Janet articulated, during her third interview (see page 220). Maclaren (2014, 97) argues that the positivity of touch is only available “*when it occurs in the context of trust*”; within the narratives of some of the participants are indications of this aspect of existential trust being re-established. For these couples, touch reasserted a past knowing and promise of “*futurity that is inherent to intimacy*” (Jacobson, 2014, 103), although, for most, it remained tempered by the threat of heart disease. This was not the case for all the dyads in this study as already highlighted. Two couples found they became increasingly divided from a corporeal and relational perspective. I am drawn to an argument by Jacobson (2014, 110), when I reflect upon this, who states:

“The ruin of intimacy is when we become deaf to [the other’s] entreaties and, thus, lose our practice of benevolent touch – that is, of responsive touch: when we cease, in other words, to engage in making (a mark of activity) a way of being-at-home (a mark of passivity) with the other.”

I suggest that disruption to corporeality and intercorporeality in participants of the Farm Angina Project, affected their inter-subjectivity and consequently trust within their relationships. Incendiary to this disruption were “clumsy” attempts to conceal that which is most difficult to hide in longstanding relationships, the tacit inter-bodily knowing between partners. This also added to an erosion of their existential trust, which seeped in to other lifeworld dimensions. I will discuss this in more detail towards the end of this chapter.

8.3.5 Dyadic coping and support

Although this study looked at each member of a farming dyad, individually, with regards to their experiences of SAP, we are still able

to consider how couples coped, interdependently. Traa et al. (2015, 85), in a recent systematic review of dyadic coping research, assert that the “*solely individualistic view, where the patient and partner experience [cancer] separately and deal with it in a role-related perspective [as patient and caregiver] seems outdated*”. It is easy to construe the same might be applicable to other chronic conditions, e.g. heart disease. Indeed, the authors suggest “*severe chronic illnesses may be best considered as stressors concerning both partners simultaneously*” as a “*we-disease*” (Traa et al., 2015, 86).

The Farm Angina Project demonstrated that, even within close couples, illness should not always be construed as a “*we-disease*”. As detailed, the existential suffering-wellbeing trajectories of individual participants and participant groups (men versus women) varied; so, too, did their expectations of each other, during illness. Recognition that illness may bring differing ideas regarding its management for couples is important. I assert that couples may present with dimensions which could be termed “*we-disease*”, but underlying this is a more powerfully directing “*my-disease*”, from both partners, which also should be considered.

Within the Farm Angina Project, couples responded to illness in different ways. However, common to most was their reluctance to accept recognised roles associated with SAP, as already discussed. Consequently, the inter-dyadic support offered and received was not always congruent with each partner’s perceived needs.

Dyadic coping is defined as a circular bidirectional sequence in which partners attempt to help reduce stress perceived by the other. It is “*an interplay between non-verbal stress signals of one or both members of the dyad (e.g. stress communication), the perception and decoding of these signals by the other partner and his / her reactions (e.g. [un]supportive behaviours), and joint dyadic coping efforts*” (Traa et al., 2015, 87). It is argued that a supportive spouse is an important resource in coping with illness (Walker and Luszcz, 2009); however,

they can also be a source of added stress, to both the one offering support as well as the recipient (Benyamini et al., 2007).

The Farm Angina Project found that participants held similar illness representations, based on piecemeal medical explanations, despite most of the women being excluded from clinical interactions. The emphasis, however, on lifeworld-led behaviour in the men and biomedical temperance in the women meant that there was often divergence in how this information was acted upon, hence, a tendency towards support undermining from a number of the women (Benyamini et al., 2007). This included partner maximisation by some of the women (e.g. Jane) of the seriousness of their husband's illness, leading to spousal overprotection through covert behaviours, such as staying awake at night, as well as overt means, like ringing him constantly at work. Whereas others, such as Brenda, exhibited minimisation of her partner's predicament and therefore less need to be supportive, e.g. continuing to work and provide no assistance on the farm. Both these supportive behaviours were at odds with what their particular husbands required and were therefore not seen as beneficial to their wellbeing. Both Jane and Brenda also found these tactics unfulfilling, (possibly due to the negative way their spouse's responded to them) and were made to feel guilty, even though they were unable to articulate why. Their men's reluctance to instruct on the sort of support they needed appeared to fuel the women's frustrations in this regard.

8.3.6 Cultural influences

As discussed in my review of the literature, strong gendered social identities and roles exist within British farming culture, sharply contrasting farming men and women (Price and Evans, 2009). It is argued such identities and roles have developed, over the centuries, in response to the needs of the profession and survival of the farming family way of life. They revolve around the male being the principle farmer and breadwinner, and his female partner as wife, mother and

“emotional caretaker” to the family’s needs (Parry et al., 2005). However, just as farming has changed, over the last fifty years, so too have the roles of farming men and women and a new fluidity of roles on the farm is now recognised (Riley, 2009). This has also led to a subtle freeing of women, from farming responsibilities (Price and Evans, 2009); although this appears to be not without repercussions, when the farm is threatened, as my study indicates. It was observed that the women who worked on the farm found the actions of their men (to work on despite SAP) less stressful than those women not directly involved. This might be due to these women holding similar cultural orientations as their partners. It was also clear that those women not directly involved in farming, perceived incongruence between the severity of their partner’s disease and his actions, which they viewed as risk-laden. This led these women to conclude that their partner was being reckless with his health and, subsequently, their relationship. They felt somewhat betrayed and became increasingly mistrustful, attempting to be (either covertly or overtly) more controlling of his behaviour, to limit risk, in keeping with the caregiving role they felt compelled to uphold. Indeed, other studies have shown how women marrying into the farming lifestyle can find its customs difficult to reconcile, compared to their pre-marital lives (Danes and Lee, 2004). Tellingly Ramirez-Ferrero (2005, 116) found that non-farming (or as he calls them *“industrial”*) wives of farming men were *“much less emotionally invested in, and connected to, the land”*. Echoing elements of my own study he concludes that unlike their men-folk *“who see farming as a way of life, industrially oriented women were more likely to see farming as an occupation like any other”*.

This may well have led to relational tensions for the participants in my study; some of the men felt their partners did not understand them and so became less communicative, moody, even hostile, which led to deterioration in their spouse’s inter-subjective wellbeing. Here, then, it can be suggested that illness intrusiveness was more impactful for non-farming women, than it was for the farming wives. Furthermore this

highlights how disarticulation of women from the workings of the family farm is not without its problems, when crises, such as illness, necessitates an increased reliance upon them to fulfil more traditional “*emotional caretaker*” roles (Parry et al., 2005). This can lead to difficulties for the women, fulfilling multiple duties, due to lack of time, as well as conflict between “on-farm” and “off-farm” identities / roles (e.g. such as in Brenda’s case).

8.3.7 Spousal role

Throughout the study the notion of ‘role’, particularly for the women / caregiver has been discussed. The idea of being a wife, lover, carer, and worker all at the same time appeared to place a great pressure upon the female participants, and made it difficult to reflect where and how they fulfilled all or any roles, let alone, how they viewed themselves. This has been evidenced in other studies. Heron and Skinner (2012) highlight the pressure farm women place upon themselves, through perceptions of their caring roles and responsibilities, seen as integral to the sustainability of their farming way of life. The authors found that, “*alongside an embodied sense of pride, the farmwomen also acknowledged feelings of stress and lack of choice when they described their family care roles*” (Heron and Skinner, 2012, 239). This was not due to a simple victimisation of the women as exploited carers, however. Rather, it was their personal drive to maintain the productivity and success of their farm business that led to such behaviour. All the women in the study by Heron and Skinner (2012) defined their health in terms of being productive. Their duty to care for the family and the farm was seen as over-riding any concerns about their own health. Likewise, undertaking extra farm-work also appeared to mean that feelings should be repressed, because these were viewed as detrimental to productivity. Heron and Skinner (2013, 245) conclude that the women in their study held:

“A commitment to farm productivity, which they viewed at once as a moral responsibility and prime motivation that transcended their views of their own health and wellbeing, despite evidence of significant physical and emotional stress related to living, working and caring on farms”.

The Farm Angina Project evidenced the same body opacity in female participants, in order to maintain the new order brought about by their spouse's SAP, along with similar detrimental consequences.

Karner et al. (2004) undertook a phenomenological study of 25 spouses, one year after their partners had suffered a cardiac event, to investigate how they viewed the support they had given related to lifestyle change. The authors found that participants held five differing views of spousal role, two of which I referred to earlier. These are, (i) the participative role, characterised by co-operation and open communication between partners, with the spouses encouraging support of collaborative decision-making; (ii) the regulative role, characterised by the partner's authoritative attempts to control the behaviour of their ill spouse; (iii) observational role, with an emphasis on passive support; communication was variable, as was a positive or negative attitude towards their spouse's health behaviour attempts; (iv) the incapacitated role, characterised by the spouse's inability to be supportive, either through their partner's unwillingness for them to be involved, or due to them needing support for their own issues; finally (v) the dissociative role, where partners were seen to separate their own lifestyles from that of their partner, when illness threatened change; their attitude was often authoritative and dismissive of benefits related to behaviour change; a wish to maintain their own lifestyle superseded their partner's needs.

Elements of all these states were seen at differing points across the year of the Farm Angina Project that appeared both socio-culturally and relationally led. Using these categories, one could argue that Brenda's

first two narratives demonstrated both an incapacitated and dissociative role towards her husband. She spoke of not knowing how to help him, due to his unwillingness to speak about SAP. At the same time, she was more assertive that he needed to help himself, first, leaving her to get on with her parental and off-farm duties. Brenda admitted to work pressure, away from the farm, which limited her ability to give any time to care, practically, for her spouse. However, following on from her own bout of ill health, Brenda spoke of a more “*participative*” role towards supporting her husband. There appeared a number of reasons for this; the first was her newly-gained appreciation of the fear and trepidation being admitted to hospital with chest pain stirred. This helped Brenda to reflect upon her lack of spousal support, earlier in the year, for which she became regretful. Secondly, this change in Brenda also appeared to be linked to improved communication between herself and her husband, possibly helped by his own health gain, as well as the participative support he offered during her own ill health. It was clear from this one participant that support roles can change due to an array of circumstances, and so should be understood as being temporal and fluid.

Over the year of the study, the way dyads supported each other and coped with SAP changed. For some (although not all) dyadic coping matured, as they learned how to live with SAP, how to share each other’s vulnerabilities and provide mutual support. Allied to this was a re-establishment of relational trust, born out of improved intercorporeality and communication. Support within dyads was an important factor; however, it was a complex, temporal entity, sensitive to a range of internal and external considerations. When mutual support was beneficial, it held the unity of couples; however, when lacking or there was a mismatch in support offered or received, this appeared to add to the strain couples experienced, in the face of illness.

8.4 Erosion of Existential Trust

The notion that participants were experiencing an erosion of existential trust in the world, possibly due to the introduction of illness, first came to me as an embodied feeling, at interview and again, whilst listening to recorded narratives. This continued to pervade my thoughts during analysis, until I was unable to ignore it. Focussed consideration followed where I perceived examples of a loss of existential trust within the differing lifeworld dimensions of the participants, related to corporeality, spatiality, relationality and temporality.

Consideration of mood as a background upon the world was discussed in chapter five; I assert that 'deep trust' is one such state of "how-one-finds-oneself-ness" (Stolorow, 2013). Frederiksen (2014, 174), considers that trust "*is a mechanism which allows us to make sense of the world and secure the continuation of social order*", based on a person's "*habitus ... the interpretative schemata and embodied dispositions which shape the way they think, act and perceive*". According to Mistral (1996, 196; cited in Frederiksen, 2014, 174):

"Habitus is habit: the continuation of the past into the present increasing the predictability of the present through routines, taken-for-granted assumptions and rituals. Consequently trust as habitus becomes the main part of ontological security of basic trust".

Here, SAP disrupted the habitual worlds of the participants and, in so doing, their trusting reliance upon it. The male participants' illness raised uncertainties about their self-identity and social role as farmer. As evidenced in other studies "*farming is more than work – it is also a rural way of life. Farming shapes self-identity and engaging with the land*" (Lovelock, 2012, 585). In this regards the threat to freedom SAP wrought may have been potentially more impactful for these men, than say an office-worker, who does not associate his profession with lifestyle or culture, and is not so reciprocally pressured by it. Thoughts regarding life and death, the impact it would have on loved ones, wellbeing, the farm, were a tangled present for the SAP suffering

participant's, although not often spoken about. Medical tests and potential treatment were a frightening prospect for most and being unable to foresee what the future held added to their sense of growing vulnerability. In the midst of all this there was a steady corporeal deterioration, the men became weary and more wary of whom and what they might trust.

I found the marked change in some couples' relational stability, apparently due to the introduction of SAP, surprising, making me question whether this was down to pre-existing relational problems, or something less conspicuous. Certainly, illness disrupted each participant's interrelated lifeworld dimension. I assert that all the participants also underwent erosion of existential trust, as a natural mood, due to the uncertainty which illness brought to their sense of freedom.

Trust then appears part of a person's natural attitude to the world, born out of their taken-for-grantedness (Mollering 2001). Ratcliffe et al. (2014, 3) argue that when it is lost, so is the "*habitual confidence that more usually permeates all experience, thought and activity*". Courtright (2013, 50) describes trust as a natural attitude of "*existential trust*" and offers this detailed definition:

"Existential trust is a primordial and atmospheric (generalised, ambient, and diffuse) manifestation of trust that constitutes a fundamental way of being in relationship with the world as a whole such that one feels supportively upheld, vulnerably open, orientationally attuned, and demanded in relation to this world, with the overall effect of feeling at home in it."

Taking this definition and considering the participants' journeys as evidenced by the Farm Angina Project, one can easily observe that neither dyad member regarded themselves as "*supportively upheld*", particularly during the initial stages of disease. Likewise, they actively strove not be vulnerably open, in order to try and conceal perceived

weakness. Finally, the world as an alien place, certainly not home, was mentioned by a number of participants.

Loss of trust can, therefore, be seen as a perspective shift, undermining self and identity (King et al., 2008). The Farm Angina Project participants spoke about this, examples strewn throughout the landscape of their lifeworld; primarily related to their lived body experiences, at other times spatial, temporal and / or relational aspects. From within these existential dimensions, erosion in existential trust began to emerge, captured through a distilling of their reflected thoughts and actions at interview. However, participants did not speak of losing existential trust, directly. It was alluded to in more subtle ways. They first described a change in their world-experience, in bodily terms, e.g. Arthur being made to “*feel small*” by the doctors’ “*big words*” (page 171), and Colin suddenly becoming “*nobody*” while enduring bodily objectification on the ward (page 168). Such corporeal fragility brought with it a heightened sense of others as existentially threatening (Ratcliffe, 2009). The body for the men became something more than just a medium of perception; it became a conspicuous object of others’ perception. During this state of unwanted regard, the world became a more intimidating place; this altered the men’s “*background sense of belonging to the world*” (Ratcliffe, 2009, 208), as well as their ability to trust in it. This led to a loss of spatial trust, spoken about by Kevin, who feared the isolation of his farm now (see page 198) , and also by Colin, who suddenly did not trust the fields he had worked since he was a boy (page 166) . A number of the women also spoke in terms of spatial mistrust, often related to their partner’s wellbeing, occasionally about themselves trapped within the confines of a home that suddenly felt less familiar (from Jane and Brenda, page 210).

It is important to illustrate how existential trust might be affected by illness and how this can colour the viewpoints and actions that participants take within this mood. Such a condition may become a cyclical state that further erodes a person’s sense of wellbeing and suffering; permeating all dimensions of their lifeworld and spoken of as

disruption to body, space, time or relationships. Throughout my findings I highlighted how such an erosion of trust was described within these interconnected facets. However, I will now consider trust within the relational dimension of participants in more detail, as this featured prominently within their narratives.

8.4.1 Relational trust

Relational trust was a constant, temporal theme, within participant narratives, which was particularly embedded in discussions about spousal support and healthcare, as well as their interactions with me as the “researcher”. Mollering (2005, 4) refers to trust in another person as a *“leap of faith based on interpretation”*. However, relational trust is not simply a contract with others; it is also interaction with oneself, as Kalman (1999, 146) states: *“More fundamental than a trust in others is a trust in oneself, in others and the world. Trust in ourselves is co-constructed with trust in others”*. As already evidenced, eroding self-trust related to body, particularly for the men, had a reciprocal and spiralling effect upon the world, spreading into the other existential lifeworld dimensions, before reflecting back on how the body was perceived. Trust, as an intentional state, was articulated most often from a relational perspective, which is not surprising, as this is where most people would probably believe it lies. Nevertheless, I assert it stemmed from a loss of existential self-trust and a perception of what one *“might not be”*. SAP eroded participants’ embodied self and therefore their being oneself in relation to others.

Both the men and women spoke about whom they could confide in and what this shared information might contain; varying relational topographies of trust were mentioned. The men were typically less likely to share their vulnerability than the women, who did confide in other female family members or close friends. However, for both members of the farming dyad, relational support was limited, even between each other during the early stages of SAP. Some of this

appeared self-imposed by participants, and influenced by cultural attitudes, to which I will return.

Frederiksen (2014b, 132) discusses how a person goes through a risk-trust evaluation, when *“dealing with uncertainty in social relations ... In trusting, one is delivered in to the hands of the other, whereas without trust one must be on guard”*. If trust is undermined by suspicion and risk, the *“preoccupation with the others motives become paralysing”*.

In this respect, a number of the men found their partners support undermining, and healthcare lacking of understanding, in both cases, most commonly related to their farm-work. A number of the women experienced deterioration in trust in their relationship with their partner. This was noticeable in those women who were not connected to the farm in a work sense; as already discussed. As Frederiksen (2014, 14) states: *“if one has concerns about trust – whether it may lead to regret – one has in fact already entered a state of risk”*.

Jane, in particular, was affected by a loss of relational trust, talking about her partner in the past tense, *“the guy I met sixteen years ago is gone”*, as well as expressing fear that the future may hold nothing for them. During early interviews, there were examples of narrative foreclosure, defined as *“the premature conviction that one’s life story has effectively ended”* (Freeman 2000, 90; cited in Ratcliffe et al., 2014, 2). Her relational story with her partner appeared no longer sustainable, due to his *“stubborn”* commitment to a job *“that may end up killing him”*, and with this her ongoing commitment to their conjoint life narrative. Indeed, Jane did leave her partner, before the end of the study. During this upheaval she spoke about her home becoming just a place, devoid of connectedness; from this one might construe that Jane was also casting aside the embodied cultural beliefs attached to the farmhouse (Price and Evans, 2009) in her escape from it. Her action being a rejection of the farming way of life as much that of her partner. Indeed she also spoke of him as being a victim of this life.

A number of the male farmers found their spouses' attention intrusive during the early stages of their illness. Intrusive behaviours are defined as those which invade another person's privacy. Such behaviours are not only fed by mistrust of the other person, they can also be a consequence of a need for relatedness, in the intrusive partner (Buyukcan-Tetik et al., 2013). Frederiksen (2014b, 142) states:

"When people explicitly choose to trust in very close relations, they choose to accept vulnerability. Vulnerability, rather than trust, seems a way of handling an adverse outcome in advance in order to uphold social identities, close relationships, and more general trust relations".

It appeared both members of the farming dyad had difficulty sharing vulnerability with the other; their social standing (particularly in the men) as the farmer "provider" appeared to influence this.

Weber and Carter (1998) offer a unique temporal perspective of trust that is worth consideration. Weber and Carter (1998, 9) suggest relational trust is like a thread weaving two different people together, to form a unified relationship: *"an interactional orientation between self and other whose object is the relationship; this relationship is typified by one's belief that the other will take one's perspective into account when decision-making and will not act in ways that violate the moral standard of the relationship"*.

Here then trust is a temporal structure in which *"the passing of external and internal time together, or synchronicity, is necessary for the establishment of trust"* (Weber and Carter, 1998, 13). The authors argue we only learn to trust, over time, and through the sharing or disclosures with the other person. Reciprocal self-disclosure about one's life and history are the cornerstones in the construction of trust; such revelations help us orientate to each other. Although one cannot control how another will react to disclosure, alternatively, we have the control to disclose, or not to disclose, during the process of relationship building. Over time, relationships create their own history, where reciprocal disclosure shifts from the superficial to the more personal

and intimate. When challenged by illness, one can argue that if such a defining characteristic of self is not disclosed, in a timely manner, then that can threaten trust within the relationship. It is important within any relationship that each person believes the other upholds the core dynamics of trust, even when not in their presence. If there is a suspicion that this is not the case, then vigilance and mistrust develop, threatening the stability of relations (Weber and Carter, 1998). Certainly, during the early part of the study, most of the women felt that their partner's disclosure had not been forthcoming early enough; this led them to voice suspicion that hidden problems remained, once his SAP was known. The men's actions out on the farm were also seen as threatening, by some of the women, to the maintenance of their relational trust. All this corroded their deeper sense of tacit trust, about themselves, others and their wider world. This was extended to the healthcare they received by a number of the participants.

8.4.2 Trust and healthcare

Dinc and Gastmans (2013) undertook a literature review of 34 articles, investigating trust in nurse-patient relationships. They found that trust in such circumstances was a relational and temporal entity, which could be lost and re-established. They concluded that a nurse's professional competencies, interpersonal caring skills and being seen as trustworthy were integral to the development of patient trust. However, Dinc and Gastmans (2013) also warn that such trust is fragile and easily hindered. Factors that hampered the development or sustaining of trust included language barriers, due to the nurse's reliance on the voice of medicine; de-personalising patients through the use of a diagnosis title, or bed number; as well as other work factors, such as busy workload and lack of time. The outcomes for patients of a trusting relationship were mixed, although for those with chronic illness *"trust was a meaningful and powerful component in shaping their illness experience"* (Dinc and Gastmans, 2013, 507).

Existential and relational trust was not helped, in this study, by couples' interactions with medical professionals. Factors including, the doctor's reliance on the voice of medicine when discussing SAP, the women being barred from these consultations, and then offered only piecemeal, edited versions by their partners, all contributed to an insipid erosion of relational trust in dyads. Furthermore, several men spoke of feeling dehumanised by the care they received, particularly in hospital. Hence, they were subjected to the dichotomy of needing medical assistance, yet feeling devalued in their dealings with these services. In findings similar to a previous study by Meyer and Ward (2013), the SAP sufferers in this study were dependent upon the doctors to ease their symptoms, but were not given the opportunity or time to trust them. Rather, they voiced having to trust in the healthcare system to which they had conceded illness and vulnerability, rather than individual doctors. However, there appeared a difference in the way the men in my study viewed the hospital doctors and their own GP. There was an expectation of trust in the latter, which had built up, over time, through familiarity, continuity and reinforcement of positive / helpful interactions. In some cases, these expectations were not now being met, through retirement of the established GP, reorganisation of the way the surgery dealt with appointments, and perceived time pressures to which GPs were now subject. Access to such services appeared increasingly restrictive. These changes added to the dyads sense of abandonment in some ways by the care services. This leads me on to the final phenomenon explicated from the findings of the Farm Angina Project, related to the existential suffering caused / perpetuated by the healthcare study participants received.

8.5 Existential Suffering Caused by HealthCare

The Farm Angina Project showed that healthcare personnel did not appear to acknowledge the lifeworld needs of the SAP sufferer, or their partner. In some cases care was dehumanising and therefore contributory to individual and dyads' existential suffering, mostly

through a lack of dignity. Jacobson (2009, 1538) highlights two forms of dignity, these are “*dignity-of-self (which) is an individual quality of self-respect*” and self-worth and “*dignity-in-relation (which) refers to the ways in which respect and worth are conveyed and mirrored through individual and collective behaviour*”. The author argues that dignity violation is more likely when one actor is vulnerable due to illness or oppression, and that such violations are well documented. Experiences of suffering and violation of dignity due to care were evidenced in my study, supporting previous research findings (Berglund et al., 2012; Jacobson, 2009; Wiklund-Gustin, 2011). This appeared to influence the ways participants experienced SAP individually and as a dyad.

Based on the violation categories posited by Jacobson (2009), a number of the men suffered (i) indifference, where care needs remained unacknowledged (as voiced by Colin); (ii) intrusion; where privacy was not respected (as with Kevin, in the angiography suite at HCH). Many of them also spoke of feeling, (iii) objectified, being treated like an object rather than a person (again from Colin) and spoken to using the language of medicine, which further alienated them from themselves (as mentioned by Arthur). In a study by Berglund et al. (2012) such medical objectification led participants to practice exclusion from their disease, because they were unable to identify with it on their own terms. “*Patients feelings of being mistreated, not listened to, excluded from decisions, objectified, and incorrectly treated lead to frustration and feelings of loneliness in the disease situation*” (Berglund et al., 2012, 6). Certainly there were elements of this within the narratives of my own study. Beach et al. (2005) found that patients who were treated with dignity during medical consultations appeared more likely to adhere to treatment and reported feeling more satisfied with care. Unfortunately poor adherence to drug regimen was a common occurrence within the Farm Angina Project, which, based on the findings of Beach et al. (2005), may have been partly due to the lack of attention to dignity they received in hospital. Some of the men were also resistive to future care offers made by outpatient

departments, such as CR; again, this may be due to previous negative healthcare experiences.

The healthcare spouse's received also had an existentially negative impact upon most of the female partners. The women's suffering appeared magnified by healthcare professionals '*disregard*' for their status, rendering them invisible and voiceless (Jacobson, 2009). It was as if they had no place in the hospital or clinic and this was reinforced by the actions of clinicians within these confines. In some cases it was also re-enforced by their spouse. Yet from this peripheral position they were then expected to step in to a central role and serve as 'carer-giver' on the farm, not least by their ill husband. Lack of acknowledgment or support for this role took its toll on a number of the women, fuelling their uncertainty, anxiety and ultimately their coping ability as an individual, as well as part of a farming dyad.

8.5.1 Death anxiety

Most of the participants spoke of their own mortality at some stage during the twelve months of the study. Mount et al. (2012) argue that death anxiety is always with us, whether we are conscious of it or not. Indeed this follows Heidegger's view (1962/2012, 279) of "*being-towards-death*" as an ever-present entity against which we measure and shape our lives. Certainly the introduction of SAP brought such thoughts to the fore in most of the participants, linked as it is with heart disease, a well-established, common cause of death. Although the possibility of death was spoken about jovially and with a stoic sense of resolve by most of the men I sensed this was more existentially troubling than they admitted. Such thoughts also seemed complicit in an erosion of participants' tacit trust in the world around them, highlighting as it did their transience within it. Heidegger speaks about self-trust as having a futural "*projectedness of one's potentiality-for being*" (Heidegger, 1962/2012, 385). SAP blunted this temporal certainty and in so doing participants trust in self. This undoubtedly

effected daily actions and reactions. Based on Heidegger one can construe that such thoughts may encourage a more authentic view of self; pushing a number of participants more keenly to farm because this helps shape their authentic self-identity, through a 'not-yet-dead' attitude. As Inwood (1997, 70) states "*awareness of one's own death snatches one from the clutches of the 'they': since Dasein must die on its own*". Exceptionally, for Kevin, this actually crystalized his desire to leave farming, at odds with the other men in the study. He was not from a long line of farmers, and so it is possible that Kevin did not "authentically" feel as connected to this way of life. The same death anxiety was voiced by a number of the women, e.g. "*being put in the next pen*" (from Alison, page 264) as symbolic movement towards death. Despite this, no acknowledgement of death fears was given by the healthcare practitioners involved in their care, according to participants, only their 'risk of death' score related to surgical intervention was offered. Again, such interactions, or lack of them, appeared to add to participant's existential suffering and triggered reactant behaviour in some of the men towards maintaining a sense of self-identity on the farm, despite the potential risk to health and safety such actions posed.

8.6 Summary of the Chapter

Within this chapter, I have detailed main temporal findings from the Farm Angina Project and discussed these in light of other research. I assert that, based on the study's findings, participants suffered corporeal destabilisation, due to SAP; this then affected their intercorporeality. Such destabilisation of their primary standpoint on the world distorted how they viewed it, existential space, time and others all took on a differing perspective that was somewhat alien to them. The men experienced differing suffering-wellbeing journeys related to SAP than the women. In illness, the men attempted to hide body disruption, in order to maintain their sense of self-identity and freedom; integral to this was their perceived farming identities and roles. The women

became body-invisible, in order to conform to dutiful caregiving stereotypes and, in some cases, distance themselves intercorporeally. I assert that both undertook this subterfuge to conceal sudden vulnerability, which was inconsistent with their worldview. This led to an erosion of existential trust, which further affected the mood of their lifeworld. Finally I discussed how healthcare did not appear to acknowledge the lifeworld needs of the SAP sufferer, or their partner. In some cases care was dehumanising and therefore contributory to individual and dyads' existential suffering, through a lack of dignity. Although heart disease caused some participants to consider the possibility of their own death, anxiety related to this also did not appear to be recognised by those charged with their care. In the next chapter I will detail how the findings of the Farm Angina Project, as well as the philosophy underpinning my hermeneutic phenomenological research with a longitudinal approach, can inform future healthcare provision to farmers with SAP, and their partners.

Chapter Nine: DISCUSSION, PART TWO: INFORMING HEALTHCARE

“this tablet, not that
a precarious balance
life versus no life”



“Why’ve I got all these pills rammed down my throat and, they’re stopping me doing, anything, so you ask the question... oh well, they, they are given you for a reason because you’re ill...you can start taking them now, and you start taking them and you can’t walk 10 yards, and you think well, being farmers, you know we’re physical people, what do you do, oh we shan’t take that one, we shan’t take that one...”

Colin

9. Chapter Nine: DISCUSSION, PART TWO: INFORMING HEALTHCARE

9.1 Introduction

In this chapter I will consider how my findings, and research philosophy adopted by this study, can shape the principles behind effective SAP rehabilitation for farming dyads. A phenomenological-informed, LLC approach will therefore be discussed. At the same time I am wary not to give the impression that this is the only valid strategy for supporting those with SAP. As Benner (2000, 6) reminds us, a balance of approaches is plausible:

“Technical cure and restorative care need not be mutually exclusive. That is, there is no reason to hold an oppositional choice between the powers of nurturance, lifeworlds and embodied capacities to the exclusion of therapeutic medical interventions, so long as those interventions do not strip the person of their powers and lifeworlds”.

Indeed, my study showed that medical / surgical interventions were beneficial to most participants, through reduced symptoms, which may have had a beneficial effect upon their lifeworld's and subsequent wellbeing. However, as also discussed, there were large gaps along their care journeys, as well as episodes of insensitive care, that eroded dignity, and which appeared to cause unnecessary individual, as well as dyadic, existential suffering. Consequently this may have had a detrimental effect upon participants' acceptance of follow on medical / healthcare support, such as CR, through a loss of trust in the service. Such oversights did not appear due to any one person; rather participant's tended to blame the system of care, particularly time and space constraints, where the voice of the lifeworld had no opportunity to emerge. That said, one might also assume that the existential lifeworld of patients is not a perspective that many clinicians recognise, due to their biomedical training, and tendency towards a Cartesian outlook.

Certainly I had not come across such a perspective as a physiotherapist prior to this study. However, the ability to be able to reflect upon the lifeworld consequences of medical care, may help to limit dehumanising practices and protocols. Although issues related to accessing medical services, intransient timetables, limited space and time during consultations were all important criticisms of the healthcare participants received, these thorny issues are not my focus here. Rather the ethos behind effective LLC will now be discussed.

9.2 Striving for “Insiderness”

The Angina Plan (Lewin et al, 2002) remains the cornerstone of main stream CR for SAP sufferers, focussing as it does upon correcting misconceptions and maladaptive beliefs’ related to SAP within a broader self-management programme (as discussed in my review of the literature). However my study suggests that perceptions of SAP are not just shaped by a lack of understanding of the patho-physiological mechanisms related to illness, as advocated by the Angina Plan. Although Lewin et al., (2002) suggest reassurances based on this premise do improve patients’ quality of life with SAP, by bolstering their confidence and ability to be active. Rather the Farm Angina Project supports the arguments of Felder and Robbins (2011), who state that the impact of illness is based on how a person sees it affecting their place in the world and culture. My study also evidences that this occurs in the partners of those suffering SAP.

A number of the men in the Farm Angina Project felt that the ‘*one size fits all*’ attitude of healthcare ignored their own ‘*insider*’ experience’ of SAP; leaving them facing the difficult dilemma of following a medical discourse at some odds with their own intuitive sense of purposeful journey and self-identity. Integral to this, for most of the male participants, was being able to farm, despite illness. For the women, knowing how to provide support and being acknowledged in this “care-giving” role was important to them, from both their partner and

healthcare. Recognising their own existential lifeworld disruption in the midst of their husband's illness, and attempting to maintain a sense of self was also concerning for the women at this time. Therefore a LLC approach to patients with SAP as well as their partners could be potentially more effective than the Angina Plan alone, in helping them to understand and assess the impact of this illness using their own terms of reference. By incorporating such meaningful care we are also able to limit the '*one-size-fits-all*' criticism often levelled at positivist CR practices (Clark et al, 2012).

As Todres et al. (2014) highlight, meaningful care should include some consideration of patient 'insiderness', seen as a foundational first step to providing effective LLC. As already outlined, my own study demonstrated the importance of gaining a similar degree of 'insiderness' with regards to the partners of those with SAP. This is because their own existential journeys are destabilised by their spouse's illness and this can then reverberate negatively within couples, further adding to each person's distress. It can be argued that individuals and couples should be treated in tandem and in a humanised way, avoiding the pitfalls evidenced within the Farm Angina Project, related to violations of dignity. These included "indifference", "intrusion" and feeling "objectified" by care (or lack of it) for the men and feeling "disregarded" from a number of the women.

Key to LLC is the ability to connect with patients in such a way that engenders trust (Galvin and Todres, 2013). This involves a position where the therapist is able to share vulnerability and, in this way, be authentically present to the patient. In Thompson's (2012) powerful reflection on interviewing Iraq War Veterans, she states: "*it was here I came to understand that the practice, presence, and the art of inquiry were the very terrain of vulnerable beings*". By offering these men the opportunity to speak about their traumatic experiences, while connecting in an embodied way, healing was made available.

Thompson (2012, 839) argues it was not through anything she said, but through her assertion to *“deep listening”* and own acknowledgment of vulnerability, while being party to their experiences. Carel (2009) also highlights the importance of recognising another’s embodied vulnerability, during illness, as well as one’s own. In so doing, she argues, one attains a level of open communication which allows creativity and flourishing to occur. Although she accepts that illness, as a multifaceted experience, brings with it *“bad things”* such as pain, fear, etc., it can also be an opportunity to change, *“a tool for self-development and as arousing feelings of resilience, competence, wisdom, appreciation, love of life and self-respect”* (Carel, 2009, 216).

Todres et al. (2014) question whether striving to grasp another’s *“insiderness”* is more important than outcome, the energy of such *“reaching forwards”* having a more powerful effect on the other’s wellbeing, than an outcome-based approach alone. This concept is not new; two decades earlier, Van Manen (1998) recognised the need to connect more meaningfully with those in our care, stating:

“Increasingly the health science professional is becoming aware that people require not just healthcare assistance, surgical intervention, or pharmaceutical treatment, but that the professional must be more involved in the way that people experience and live with their problems in a different, sometimes deeply personal and unique manner” (Van Manen, 1998, 16).

Through my own embodied enquiry, I experienced a sense of shared vulnerability and, during those moments, the spark of what I perceived to be a mutually healing connection. This took me by surprise, particularly as I visited participants as researcher, not clinician. My questions were open-ended; I offered the interviewees no advice, in return, only time, space and a commitment to listen. Yet, a number of participants felt impelled to tell me that they had valued our meetings together, particularly the partners of those with SAP. MacLeod (2011) suggests that interviewing care-givers may assist them to reflect, better

understand their own experiences, and gain new insights; thus causing the positive response I noted:

“The researcher embodies theory, the participant has the experience; these two elements become entwined as these individuals interact. By entering into a relationship with the participant, at a time of disruption or uncertainty, the researcher becomes a partner in the experience. The creative presence of the researcher enables the participant to have insight into the experience” (MacLeod 2011, 246).

Galvin and Todres (2013, 172) call this “*being prepared*” to strive for “*insiderness*” and shared vulnerability “*embodied open-heartedness*”. Part of this process is being able to hear the voice of the lifeworld and reflect this back to the person who is divulging themselves, in this way. Although Galvin and Todres (2013) discuss this from the position of therapist, it struck me that if one could encourage couples who were struggling to undertake the same degree of open communication and time to listen, existential wellbeing from within these dyadic encounters could emerge. I will return to this in the next section.

9.3 Hearing the Voice of the Lifeworld

Toombs (1992) emphasises that clinicians should take up a perspective of “*illness-as-lived*” by the patient, learning to hear the voice of the lifeworld, in order to better understand their suffering and then be able to offer appropriate support. Barry et al. (2001) explored the idea of allowing the voice of the patient’s lifeworld to permeate consultations, arguing that based on their analysis of 35 case studies, it leads to better outcomes and more humanised care. Barry et al. (2001) concluded that many of the doctors they evaluated were able to switch between styles of interaction, using the voice of medicine and lifeworld, interchangeably, to some extent. However, they found that doctors struggled when dealing with chronic conditions. Where the illness was much more a lifeworld issue, they observed doctors blocking or ignoring the patient’s voice of the lifeworld, because it did not fit their purely

technical notions of success. Coulehan (2012, 728) talks of a similar model, he calls *“compassionate solidarity”*. It *“begins with empathic listening and responding, which facilitate objective assessment of the others’ subjective state”*. The author argues that such an approach *“requires the physician to develop reflectivity and self-understanding”* which in its self can be a *“healing, hope promoting act”*. The emphasis for Coulehan is on promoting within the patient a sense of *“deep hope”*; an existential sense of meaningfulness and purpose in spite of suffering, often associated with illness.

Certainly undertaking a hermeneutic phenomenological approach, and interviewing participants more than once, with no pressing time-limits, as well as in their homes, allowed the voice of the lifeworld to emerge. A sense of relational trust quickly established itself within these encounters, assisted by some of the strategies outlined in my methodology. Unfortunately, in practise both cultural and, more commonly, structural constraints i.e. time-limited consultations, weak continuity of care, limited space, etc. appear to temper the possibility of such interactions (Lo, 2010).

9.4 Upholding Existential Dignity

It was apparent within my study that participants suffered existentially through the lack of dignity afforded them, at various points of their SAP journeys, predominantly by the health professionals charged with their care. None of the participants in the study were invited to speak about their lifeworld experiences with SAP by clinicians, (other than to me). This led many of them to suffer the indignity of feeling objectified, misunderstood, powerless, and isolated in their plight.

Following on from the previous section, Parsons and Hooker (2010, 345) argue that dignity can be promoted by allowing patients the time and space to talk about themselves. Their premise is that a person’s narrative provides the listener with some idea of their sense of self. The authors suggest that clinicians need to gain *“narrative competence”* to

allow dignity to flourish; *“if our view of dignity as primarily embodied, relational and vested in identity is correct, then it follows that dignity will often be enacted through narrative, and will mostly become meaningful in a narrative context.”* Parsons and Hooker (2010, 347) suggest that the narratives patients and carers share *“constitute the opportunity for the demonstration of the sometimes fleeting and subtle forms of attending, validating, caring and responding that constitute relating. This ‘microethics’ may be dignity-enhancing.”* It is important to consider that the “carer” may not be a healthcare worker, but rather the partner of the patient, or other family member. By speaking openly with each other in this way, some dignified reciprocity might be attainable. Allowing self and others to share experiences and more, their fears and vulnerability, is not without its difficulties, which I will consider in the next section.

A recent paper by Galvin and Todres, (2015, 413-4) describes dignity as being the *“restoration of something valuable in oneself”* linked to *“cultural belonging, sense of place”* and the *“preciousness”* of life due to our sense of finitude. Similar to Jacobsen (2009), the authors argue that dignity is both experiential and relational. They also suggest that there is a deeper existential mood of dignity which is primary to other emotional states such as joy, love, sadness, that colours a person’s experience. This *“mood dignity”* also pervades states of vulnerability and value, termed *“honour-wound – a certain feel of upholding-in-vulnerability”* (Galvin and Todres, 2015, 413). I also perceive this as a way of maintaining existential hope, trust and resilience in the midst of suffering. It led me also to consider that deep-moods can be multiple and oscillating in the same way as suffering and wellbeing dimensions. In other words a person may have both a deep sense of indignity and existential mistrust, or trust.

Erosion of dignity was not just related to patient-doctor encounters; it carried through in to other parts of participant’s lives or originated there, influenced by SAP. A number of participants spoke about indignity in their farming lives. Jacob described it, when neighbours had to help

with his cattle, shortly after his return home from hospital (see page 197). Behind each narrative was a sense of disappointment in themselves, and loss of self-dignity. In an attempt to uphold dignity during a state of vulnerability, consideration of other areas of a person's life, not least their cultural affiliations may be required. This would include close relationships, and how a sense of shared vulnerability and dignity might prevail within dyads.

This is also where I perceive the value of the suffering and wellbeing lattices of Galvin and Todres (2013). They offer more targeted healthcare by uncovering nuanced layers situated between these existential poles; for instance, if spatial mobility is most effected then strategies directed towards this might most profit the sufferer. Such strategies might support vulnerability and / or encourage resilience.

9.5 Supporting Vulnerability: Sharing Experience

My study approach was non-deterministic; the aim of the Farm Angina Project was to understand the experiences of its participants, with the intention of creating experiential knowing, in that it “*relates the knowledge to our personal lives and experience; it allows us to see these experiences in a new light*” (Galvin and Todres, 2013, 62-63). The journeys outlined and discussion could, in themselves, be deemed a resource for others, to gain an empathic understanding of the subject. Indeed, it may assist participants to understand each other better and, in so doing, act as a therapeutic vehicle towards “*mutual attunement*” (Knudson-Martin and Huenergardt, 2010, 377).

A number of studies highlight the importance of understanding the other person's perspective in illness. Berg and Upchurch (2007, 945-946) state that interventions which focus upon dyadic coping appear to strengthen marital relations during chronic illness. These include “*understanding the other person's perspective regarding stress, couple communication, mutual problem-solving skills, and coordination and collaboration regarding daily management tasks.*” The authors also

highlight the temporal nature of couples coping with illness and how this changes over time, influenced by broad socio-cultural factors as well as more proximal contextual factors, such as relational quality. Certainly this was evidenced in the Farm Angina Project.

Following on from this, Greeff and Wentworth (2009) investigated illness coping, from the perspective of the family unit, confronted with heart disease. Four relevant qualities were identified. Intra-familial support, where new routines and adaptations were practised by all was seen as an important facet of resilience building. Alongside this adherence to family, time and routine also appeared to mediate family adaptation to illness. A positive outlook, and “*understanding and acceptance of new circumstances*” (Greeff and Wentworth, 2009, 312) were also prominent factors. Finally, the practice of open and affirming communication was recognised as an important component of family resilience, where caring and support are voiced and demonstrated by all members, reciprocally.

The research would suggest that integral to an effective SAP programme for farming couples is encouragement of open communication between them. However that would mean sharing each other’s vulnerability and shaking off some of the constraints of a gendered, patriarchal farming lifestyle which may not value such a perspective.

The patterns of suffering-wellbeing evidenced in the Farm Angina Project point to the autonomous male and relational female, although this could be skewed by the fact that all male participants had SAP. There were, however, elements within many of the narratives to suggest that a gendered power balance towards a patriarchal family farming lifestyle caused distress in both spouse and partner, when illness arose in the male. A lack of open communication or displays of vulnerability were commonly cited by participants; again, it appeared encouraged by their cultural affiliations. By using the findings of this study to highlight how subterfuge may not be an effective strategy for

couples, due to their deep, inter-bodily / inter-subjective understanding of each other, some progress towards a more open stance could be made. However, sharing vulnerability may be difficult for individuals, when it threatens their sense of self-identity and standing, within the family, as well as wider community.

Knudson-Martin and Huenergardt (2010) contend that mutually supportive relationships can be affected through the mediation of socio-cultural relationship patterns. Their aim is to help couples develop shared power relations, with the desired outcome that couples become able to define what “*shared relational responsibility and mutual influence look like*” and start experiencing it, in an embodied way, within their relationship (Knudson-Martin and Huenergardt, 2010, 378). In an earlier study Knudson-Martin (2006, 65) evidences five processes related to this: (i) seeing joint careers as central to their relationship and, valuing self-development within this as a symbol of equality in marriage; (b) flexible household duties, avoiding gendered divisions of labour; (iii) open dialogue regarding conflict and practising conscious negotiation; (iv) equal say in decision making, and (v) use of internal reflection. According to the author, internal processing through self-reflection helped individuals “*move beyond gender stereotypes*” and into a more balanced relationships (Knudson-Martin (2006, 67).

This study argues that striving for equality is an important facet of relational stability in dual-career couples. I consider that based on my findings the five processes outlined might prove beneficial to farming dyads, particularly where the woman has a more modern and free role. However, within the Farm Angina Project there appeared an implicit understanding between dyads that the woman’s “off-farm” work was secondary to the needs of the farm. This left some of the women, such as Brenda, feeling undermined when a situation, requiring her to be more involved on the farm, arose. Although she decided to maintain her “off-farm” work, this placed a great strain upon her, including feelings of guilt at resisting perceived cultural expectations. Certainly attention to the attitudes of both members of a farming dyad would

have to be explored related to support structures for both, during health crises.

That said, not all of the female participants in this study would consider themselves exploited by their farming lifestyle; indeed, most were complicit in its maintenance, even if they did not work directly on the farm. It was appeared that the gendered division of productive (farm) and reproductive (home) space was not a constant. As Riley (2009, 667) argues: *“gender is not fixed or given but is made or remade constantly, in response to countless different national and local sets of meanings”*. A number of the women in the Farm Angina Project worked off the farm, to supplement the family income; only two women were primary farmers. My research demonstrated a fluidity of gender roles in some of the couples, rather than the static “productive-reproductive” dualism often misperceived as part of all patriarchal family farming. Significantly, Riley (2009, 678) argues that women remain creatively adaptable, within this system, able to adopt different transitory roles, when required to do so. Thus, according to the author, they are implicit in the direction of 21st century family farming, in the UK. However, as already discussed, my study would suggest that such adaptability is not always in the woman’s own best interests, she may feel constrained by being forced in to antiquated farm support roles, through historically derived, cultural expectations. Indeed, Price and Evans (2009) offer a more critical view of farming roles, arguing that relational tensions are increasing for couples, due to the subtle changes in gender identities and roles facing farmers, in the UK. The authors state: *“that women (usually) are required to move into the family farming way of life and so are essential to the survival of it, yet simultaneously they are now considered to pose a new threat to its longevity by virtue of the increased risk of relationship breakdowns”* (Price and Evans, 2009, 9). This situation was also demonstrated in my study, with the separation of two couples during the fieldwork stages; where it appeared SAP brought relational issues to the fore, amongst other lifeworld disruption.

Gendered farming identities and roles are not exclusively detrimental to women. Coldwell (2010, 181) indicates that *“the masculinisation of farming and rural communities has not necessarily been positive for men in all aspects”*, arguing that this has meant that women have grown more independent of the farm, both educationally and in terms of income. Coldwell (2010, 181) explains that this has left many men isolated on their farms and viewed as non-modern and *“underprivileged”* compared with rural women. Hence, trapped by duty and circumstance, emancipation from such restrictive gender roles may be warranted, through support allied to a LLC approach, which enables the men to perceive they have choices when faced by illness, and thereby a sense of control.

As already indicated, highlighting the subtle cultural differences that exist within farming couples, may help each partner to understand how the other is influenced (or not) by this world. It can also help powerful partners to recognise how their behaviour affects their partner and, in this way, become more accountable for these effects. Knudson-Martin and Huenergardt, (2010, 377) are supportive of an approach: *“that challenge gender stereotypes and empower each partner to empathetically imagine the other’s experience such that they ‘feel felt’ and are mutually changed by their resonance”*.

Again, I witnessed what might be considered mutual attunement, during interviews; the space I gave participants to talk meant they not only reflected upon their own experiences, but also began to imagine those of their spouse. Towards the end of the year, this was particularly evident from the men in the study, some of whom (e.g. Jacob) were able to articulate what the repercussions of their actions were upon partners. It left me to consider whether this would have taken place, without my input as researcher or, if I had undertaken joint interviews, where such imagining might have been curtailed by the other’s presence.

9.6 Supporting Freedom: Building Resilience

Galvin and Todres, (2013) suggest in their LLC approach, that we should look to support not only vulnerability but also the freedoms of patients. Indeed Berglund et al. (2012, 2) state *“LLC embraces an existential view of being human that accommodates freedom and vulnerability by respecting patient preferences”*. In supporting these freedoms and therefore wellbeing, some consideration of everyday resilience may be appropriate.

LLC is about the pursuit of wellbeing, rather than the more blinkered absence of illness only (Galvin and Todres, 2013). The ability to farm was important to all the men in this study, despite ill-health. Being able to farm, to whatever degree illness and age allowed, seemed to help maintain a sense of self-identity and, by virtue, existential wellbeing for the men. Similarly, Freydborg et al. (2010, 1082) in their review of rural dwellers with Heart Failure concluded that these people *“should be supported wherever appropriate to modify work behaviours instead of asking older adults to cease work altogether ... to remain actively involved and symbolically involved ...”* They argue that healthcare professionals need to be sensitive to the context of patients’ lives, so that meaningful self-care programmes are formulated that foster a continuity of identity and the perpetuation of the life they wish to lead. This recognition of the male participant’s identity being embedded in their work was evidenced in the Farm Angina Project. However, supporting such work is not something that has been widely acknowledged, from a healthcare perspective. Yet, it would appear that supporting work resilience is important to the wellbeing of farmers, at least, if not their partners.

It is within the capabilities of existing CR to bolster resilience at a micro level on the farm, supporting a measured approach to the work involved, which all of the farmers in this study strived to do inherently. Adopting the FITT principle (frequency, intensity, type and time) to exercise and use of MET levels related to farming activities is already

accessible. MET levels are a method for measuring the differing energy cost of physical activities (for more information see Jette et al., 1990). The compendium of physical activities houses 821 codes of MET values that are easily accessed to provide detailed information regarding the energy expenditure of a vast array of physical activity (Ainsworth et al., 2011). This includes many activities related to farming, such as driving a harvester (2.5 METS), chasing cattle or other livestock (4 METS) and forking straw bales (8 METS) (<https://sites.google.com/site/compendiumofphysicalactivities/Activity-Categories/occupation>, accessed 01/01/15). Such a list may help to guide farmers more clearly how to work productively but safely; assuaging their partners concerns at the same time. It may also act as a guide to improving their aerobic fitness whilst working. It just requires an organised approach related to its initial presentation and subsequent management. Again one that is sympathetic to the needs of the farmers and their erratic work schedules. By focussing CR on farm-based activities in this way working towards the needs of the farmer in a more humanised and lifeworld sensitive way could be demonstrated.

Gale and Sultan (2013) found the use of tele-health equipment helped to mediate COPD sufferers embodied experience of their condition. By taking measurements and feeding these in to the equipment patients got to know the numerical significances related to their condition and when it was important to contact medical support without feeling that they were wasting their time. Again this is something that might be considered with SAP patients from rural / farming backgrounds, to help them and other family members feel complicit in the management of heart disease.

Supporting the male farmer's position on the farm with SAP is not without its problems, particularly if this were done to the detriment of a worried partner. Recognition, too, that spouses are integral to any rehabilitative process has been evidenced within this study, not just as carer / support, but also as conjoint sufferers of SAP. Some consideration of their feelings related to their men continuing to farm

with heart disease would have to be met. I suggest that for both members of a farming dyad, feeling confident that the farmer is working safely with SAP, through targeted healthcare support would be integral to the success of this approach.

9.6.1 Definitions of resilience

An ability to utilise a person's resilience, as a shift away from a deficit-based approach towards one that is asset-led is now being considered as a public health initiative (Seaman et al., 2014). By undertaking a systematic review, content analysis and interviews, Windle (2011, 163) gives a clear definition of resilience and its inherent complexity:

“Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and ‘bouncing back’ in the face of adversity. Across the life course, the experience of resilience will vary.”

Windle (2011, 165) also argues that resilience *“is interlaced with normal, everyday life”*. This view of resilience as temporal and the resilient subject as “unfinished” is taken up by Aranda et al. (2012, 555) who suggest that a person's ability to be resilient is in a constant process of *“becoming or remaking”*.

From an interpretive perspective resilience as a construct involves (i) human agency and resistance and (ii) survival (Shaikh and Kauppa, 2010). Shaikh and Kauppa (2010, 116) argue that a person is not a passive recipient of environmental stimuli; resilience therefore is shaped by the active engagement of a person to seek out relationships and support which offer this.

“Resilience connotes human agency which can be defined as intentionally making choices and taking actions”. Integral to existential human agency is *“the capacity to make sense of one’ experience, assign meaning to them and consequently make choices and take*

actions within a particular social and historical context.” (Staikh and Kuappa, 2012, 166).

Psychiatrist Victor Frankl survived the Auschwitz death camp and shortly after his liberation published *‘Man’s Search for Meaning’* (Frankl, 1959). In this he argues *“everything can be taken from a man but one thing: the last of human freedoms – to choose one’s attitude in any given circumstance, to choose one’s own way”*. He describes a form of resilience linked to resistance. In the face of extreme trauma, a man still has *‘free will’* to find meaning for themselves, even in suffering, resisting the oppressive forces that seek to thwart them. As Staikh and Kuappa (2012, 167) state *“resistance may involve negotiation where the dominant cultures are both adopted and contested. At times resistance may take the form of ambiguity where a person may walk between the spaces of dominant and non-dominant social forces.”* The men in the Farm Angina Project demonstrated a certain degree of resistance to the medical care *“imposed”* upon them, for example, not taking all their medication as prescribed.

Various papers argue that wellbeing and resilience are linked, but that someone can have high wellbeing and low resilience, or vice versa. From a positivist standpoint, resilience is seen as an individual’s ability to cope with and bounce back from adversity; however, Windle (2011) and Wiles et al. (2012) warn that, rather than seeing resilience as a personal trait, it is in fact a complex entity that involves physical and social contexts. Staikh and Kuappa (2012, 169-170) state:

“It can be said that resilient individuals require resilient families and resilient communities. However, this relationship between individual resilience and the resilience of the families and communities is not unidirectional. Communities need resilient individuals and families who can resist adverse social and political conditions and create more resources or assets.”

Much is made about the need to be resilient in order to farm successfully (King et al., 2009). Certainly most of the men’s resolve to

work on with SAP, in my study, countered evidence suggesting angina causes a premature exit from work (Jespersen et al., 2013). Whether this was through choice or duty is difficult to clarify. In truth, elements of both were mentioned. However, the men's cultural affiliation with farming also featured as a form of transcendental driver and buffer against some of the disabling effects of SAP (Furze et al, 2005).

9.6.2 Cultural transcendence, resilience and the “untenable”

There was evidence in my study of transcendence, as a form of existential resilience / supportive mood related to participants farming way of life, particularly from the men. This appeared allied to the historical significance of their farming lives, their relationship with farming landscape and its seasons. The role of farmer gave most male participants (and some female) positive meaning and a sense of being temporally part of something greater than themselves. It appeared to offer them a certain integrity and wholeness that bolstered their sense of wellbeing despite illness. It offered them the opportunity of freedom, even within the limitations of SAP. At the same time it was a temporal barometer that a number of the men used to measure their level of suffering and disability related to current health issues, as well as past markers of self (Charmaz, 2006). It appeared to buffer a number of participants from negative psycho-behavioural consequences of SAP, such as activity fear-avoidance behaviours (Furze et al., 2005). Other studies have evidenced this; Mount et al. (2007, 372) in their study of wellbeing in people with life-threatening illness observed that movement away from suffering:

“Was a consequence of the greater sense of connection to a deeper Self, and / or a reality greater than themselves. This may be understood as being due to reinforcement of their sense of ‘culture’, or worldview, and their place as meaningful participants in that culture”.

That said, within my study, there were exceptions; for Colin farming placed pressure upon him to conform to farming identities and roles he

now perceived as dangerous to his life due to SAP. The swirl of the men's farming lifeworld then, appeared to help some to stay afloat through a form of transcendental resilience, whilst it submerged others, due to its fearful weight of responsibility. As Coldwell (2010) discusses, it is important to understand the needs of the individual, and not presume stereotypical characteristics e.g. that all farmers love farming. Farming males may well be trapped by family history, duty and circumstance; and here resilience may need to focus upon strategies that encourage individual emancipation from such constraints.

The same cultural limitations can affect how couples cope with illness. According to Kayser et al., (2014) although couple coping is shaped by cultural factors in times of crises, a couple may also strive to deal with this in a way *"contrary to prevailing cultural patterns"*. The authors' state:

"When prevailing cultural patterns prove to be barriers to adaptation, they will be changed or transcended to give way to something that will enable adaptation to the illness." (Kayser et al., 2014, 283).

Certainly there were narrative strands within my own study that indicated a willingness (albeit reluctant) to move away from farming if ill health made it necessary, e.g. as discussed by Janet (see page 228). That said some stories also appeared to run contrary to this, such as George, who could not envisage any other life beyond farming, despite being in his mid-80's.

Supporting resilience in order to maintain an individual's farming way of life may well benefit their particular existential wellbeing within illness, although not always, as we have already discussed. Price and Evans (2009) are critical of various farming support organisations, such as the Farm Crisis Network and the Rural Stress Information Network, for continuing to constrain those seeking help, by supporting outdated farming identities / roles, which may be complicit in their suffering. Rather than reinforcing an increasingly untenable way of life, the authors argue that a *"credible mechanism"* is required that supports

farming dyads to readjust their perceived freedoms and constraints, in line with the demands of modern agriculture as well as wider world (Price and Evans, 2009, 9). Based on her own research Price (2011, 22) argues that specialist counselling services are required who are knowledgeable about the patrilineal culture of family farming, stating:

“Expecting farming service-users to access support within mainstream organisations, such as The Samaritans in the UK, without service providers having knowledge of farming culture is unlikely to be successful.”

Price (2011) argues this includes support for female partners, negotiating the fragility of their spouse due to his close connection to the land, where if the farm fails so do he, with a real risk of suicide; as well as the woman’s own evolving and emancipated plurality of roles. This highlights once more the need to understand not only how SAP affects a person (and couple), biologically and experientially, but also its wider cyclical interrelatedness with other socio-cultural clusters of distress (Price and Evans, 2009).

This brings us back to consider the socio-cultural, relational work of Knudson-Martin and Huenergardt, (2010) with regards to dyadic coping and use of phenomenology as a patient resource, as advocated by Havi Carel (2012). Both these approaches engage with the person to re-evaluate self and world in order to accommodate a move away from restrictive discourses, linked to either culturally shaped relations and / or illness beliefs. Carel’s (2012, 108) idea of philosophical patient support is based on the premise that illness *“involves a phenomenological reduction because it compels us to suspend our normal taken for granted way of approaching the world”*. From this the patient can be guided to thematise their illness based on their lived experiences rather than the more traditional biomedical model, gaining a *“thick account”* of it. This then allows them to uncover the impact illness has upon their existential lifeworld in a more meaningful way; helping them to build resilient coping strategies that take into account

their particular socio-cultural backdrop. Knudson-Martin and Huenergardt (2010) focus upon gaining deeper inter-dyadic understanding regarding each person's attitudes and behaviours, including how socio-cultural factors help shape these, as evidenced in this study.

9.7 Summary of the Chapter

Based on the findings of the Farm Angina Project, I have highlighted the importance of an individualised LLC approach to farmers with SAP, as well as their partners. Consideration is also given of the suffering and wellbeing definitions offered by Galvin and Todres (2013), used as a tool through which more nuanced understanding and targeted care can be attained. I have also discussed the importance of building therapeutic and inter-dyadic trust, so that vulnerability can be shared and supported, as well as encouraging an asset-led approach which promotes resilience, in spite of illness. A self-reflective approach based on phenomenology (Carel, 2012) and relational considerations based on socio-cultural factors (Knudson-Martin and Huenergardt, 2010) are also discussed; these are strategies which may allow farming dyads to reflect upon non-medical stressors that are magnified by SAP, and vice versa, which can lead to heightened disruption of their lifeworld. In this way understanding and autonomy towards SAP is developed in the sufferer, their partner and as a dyad. Furthermore vulnerability is supported, freedom encouraged and above all trust and dignity maintained.

The aim of my final chapter is to conclude my thesis, acknowledging its strengths and limitations, as well as local / national spheres of influence. I shall also make recommendations related to further research, based on my findings. The chapter concludes with a review of my own transformational journey, undertaking hermeneutic phenomenological research.

Chapter Ten: RECOMMENDATIONS AND CONCLUSION

“spring lambing
bed in the shed
counting sheep”



*“In 4 weeks’ time we start lambing, and I move house then, I move into
the, I’ve got a great big shed, and the ewes lamb in there, and er,
I’ve got a caravan in there...”*

George

10. Chapter Ten: RECOMMENDATIONS AND CONCLUSION

*“We shall not cease from exploration
And the end of all our exploring
Will be to arrive where we started
And know the place for the first time.”*

Little Gidding, Four Quartets, T.S. Elliot (1943, 197)

10.1 Introduction

This final chapter summarises the study’s key findings and draws overall conclusions. I shall re-iterate why the findings of the Farm Angina Project are important, before acknowledging the study’s strengths and limitations. I will then reflect on the study’s local and national spheres of influence, before reviewing my own transformational journey undertaking longitudinal, hermeneutic phenomenological research.

10.2 The Farm Angina Project: Review

The Farm Angina Project was a longitudinal hermeneutic phenomenological study, charged with the aim of understanding the lived experiences of eight male-female farming couples, where the male farmer had SAP. This research offers a unique and dynamic insight into the lives of farming couples, as they experienced SAP, clearly showing that SAP disrupted the lifeworld dimensions of both the sufferer and partner. SAP affected corporeal contact with the world; inter-bodily resonance and so their relationships; distorted spatial and

temporal dimensions; and challenged established social identities and roles allied to a farming lifestyle. The men experienced differing suffering-wellbeing journeys related to SAP than the women. In illness, the men attempted to hide body disruption, in order to maintain their sense of self-identity and freedom; integral to this was their social-standing and farming role. When this was no longer possible a number of the men harboured expectations of support from their partner, to maintain the farm whilst expediting their return to it.

The women became body-invisible, in order to conform to dutiful caregiving stereotypes and, in some cases, distance themselves intercorporeally from their partners. I assert that both members of a farming dyad undertook subterfuge at the beginning of SAP, to conceal sudden vulnerability, which was inconsistent with their worldview. Fear of death due to heart disease also influenced their apprehensive stance. This led to an erosion of existential trust, which further affected the overall mood of their lifeworld. Initially, neither dyad member found support for their existential wellbeing from family, friends or each other in a number of cases. However, over the twelve months of the study, this changed for some couples. This movement was in part due to re-stabilising of their lifeworld through symptom improvement, adaptation towards illness, relinquishing stressful roles, and improved dyadic coping. Most, although not all participants, reincorporated elements of their previous SAP-free lives, particularly related to work roles; these were, nevertheless, irrevocably changed by their experiences. The men tended to be more body-aware; the women less inter-subjectively assured. Relationally, illness brought some couples closer together, through their inter-dependent adaptation to it, whilst it drove others further apart. Importantly, none of these life-changing issues were considered by the healthcare practitioners charged with their care; indeed, insensitive treatment regimens added to participants suffering, in some cases, through the indignity these caused.

Based on the findings of this study, it is important to acknowledge that members of farming dyads experience SAP existentially differently, and

this can affect how they manage illness as a couple. Therefore, any SAP management programme aimed at farming couples needs to acknowledge each member's lifeworld as part of the process of rehabilitation, as well as subsequent dyadic coping strategies. Such an approach should also look to build upon these facets, concentrating on supporting individual vulnerability and resilience, so that sufferers are able to enjoy a sense of wellbeing through the preservation of self-identity, in spite of illness. Striving to maintain dignity in care, as well as a deep sense of trust appears important in this process. Dyadic coping should also be an active feature of rehabilitation, where open communication is encouraged, so each are able to maintain an active presence, sense of self-worth and appreciation of their spouse's experiences at the same time as their own; In this way allowing trust to flourish between them. A phenomenological-informed LLC approach may allow more dignified interactions that build existential trust towards self, others and the world. The Farm Angina Project as evidenced that cultural factors can influence patient and partner positioning towards SAP; in this study through the exertion of powerfully defined farming roles and identities linked to a patriarchal farming family way of life. Therefore the importance of culture at shaping a person's experiences of illness also needs to be recognised within any such care approach.

10.3 Strengths and Limitations of the Study

This study has contributed to a better understanding of the lived experiences of farming dyads with SAP. A major strength of this study is that it reveals the differing experiences and suffering-wellbeing trajectories of each person in a farming couple, when faced with illness, simultaneously, and relates these findings to their socio-cultural background. The hermeneutic phenomenological approach adopted gave voice to otherwise unspoken aspects of experience, and revealed existential lifeworld dimensions usually hidden to health professionals. Unlike most research, the philosophical and methodological structure of

this study also offers potential, therapeutic value. In this way the Farm Angina Project was revealing both through its findings as well as its application. However, as with all research, this study has limitations which must be acknowledged.

The aim of the study was to understand the lived experiences of eight farming couples, where the primary male farmer had developed SAP, over a twelve-month period. This study was undertaken within Herefordshire, during 2010-12. Since then, certain elements of care for people with SAP may have changed. A hermeneutic phenomenological approach was adopted, in order to capture their experiences and interpret them, accordingly, during analysis. By undertaking the study in this way, I took a specific philosophical stance; an alternate research approach, for example, descriptive phenomenological method, would have uncovered different meanings and interpretative endpoint. Although some attempt at categorising my findings using the wellbeing-suffering definitions offered by Galvin and Todres (2013) was undertaken, these cannot be generalised to all farming couples with SAP, nor provide specific practice guidelines. It is important to note that mine is one interpretation, where any number could be made. Neither is it representative of a particular couple; rather, it is a nuanced explication of the important issues, based on what I, the researcher, observed during interviews and uncovered during narrative analysis.

At recruitment, a slightly larger cohort was introduced to the study, with the view that a certain number of initial participants would drop out. However, most of the participants completed the twelve months, which meant that my final number was somewhat larger than envisaged or originally anticipated. Analysis was lengthier and decisions regarding the depth of interpretation had to be made to conform to study timeframes. With hindsight, a slightly smaller number of participants might have been more manageable, thus potentially offering more detailed findings. As a result, a tension remains within me that not all the voices were heard or correctly understood. However, I accept that this is the consequence of my chosen approach. Moreover, it is

acknowledged within hermeneutic phenomenology that there is never an end-point to interpretation; rather, that the spiral of understanding is ongoing.

Deciding to undertake a hermeneutic phenomenological research at doctorate level was not without its difficulties, in a practical sense, related to balancing the texture of narratives with the need to maintain scientific structure within my thesis. Mine was a constant methodological vigil, maintaining validity and trustworthiness, while also attempting to keep alive the voices of participants. In other words, finding a level that was not too personally engaged or impersonally sterile proved difficult. As I ventured towards a creative portrayal of my findings, through poetic representation and composite narratives (see www.farmanginaproject.com), so I gained a deeper, embodied understanding of the data; however, this was at the risk of distancing the work from the required standard of scientific rigour. Ultimately, a compromise had to be made, the end-point being what is offered here, with many omissions on the way.

10.4 Recommendations for Further Investigation

A number of recommendations related to further investigation availed themselves during this study. I will outline two, which are closely related to the research already undertaken, and which I see as priorities of any follow-on research that may be of use at a clinically practicable level.

10.4.1 Needs of the migrant agricultural worker

Allied to farming and yet a relatively new consideration locally, is the increasing number of migrants undertaking agricultural work in Herefordshire. The County features in the top ten local authorities for the settlement of migrant workers from Central and Eastern Europe (Bauere et al, 2007). Small settlements have sprung up on landowner

properties, which appear to maintain their own cultural affiliations. Unfortunately this can leave such communities vulnerable due to “*cultural attitudes and experiences that undermine good health and safety management*”; along with work practices that may lack competence, clarity and clear communication (HSE, 2010, 4). Herefordshire CR Team have also begun to see an increase in people with heart conditions, from these ethnic groups. I assert there is a need to better understand migrant land-workers, from a lifeworld perspective, in the same way as that offered by my study, so that appropriate care can be offered.

10.4.2 Reactance towards drug regimen

During my investigations I was told by participants that they practised reactance to help protect certain freedoms. Examples of this included the men’s intransigence to change work habits when medical regimen or partner coercion threatened their farming role; alternatively in the women, when a carer role was seen as threatening to their own independence.

Reactance theory proposes that when perceived behavioural freedoms are threatened or prevented a person will experience psychological reactance to this, and become motivated toward the maintenance or re-establishment of the particular behaviour (Brehm, 1966). Worcel (2004, 111) argues that psychological reactance *‘is a motivational state designed not only to restore freedom, but also re-establish identity’*. The author also argues that differing groups of people may have shared freedom behaviours that come with membership of their group; hence there may be such a thing as group reactance. I assert it is not surprising that members of farming dyads evidenced reactance when cultural farming ideals were challenged by apparently conflicting healthcare, particularly, it appeared their drugs regimen. More detailed work investigating agricultural workers attitudes and behavioural responses towards cardiac medicines should be undertaken. This will assist prescribers to understand why mistrust and reactant behaviours

occur and therefore better anticipate noncompliance. Such research could then act as a platform to build trust, through more lifestyle sensitive, pharmaceutical support, i.e. the type of drugs administered and prescribing routines advised.

10.5 Spheres of Influence

I shall now review the spheres of influence for this study, to date, and outline those planned, over the next twelve months.

10.5.1 Local

Over the seven years of the study, a number of practical developments have been added to the existing CR Programme, in Hereford, one of the most important being to encourage partners to become involved with their spouse's assessment and rehabilitation. As part of this innovation, discussions regarding couples coping with heart disease were added to the programme and individual, as well as dyadic support / counselling sessions, offered.

The department has also introduced an individualised home-based rehabilitation and telephone support programme for those who are unable (or do not want) to attend the group-based programmes. As part of this, patients are encouraged to phone the department, whenever they wish, to discuss aspects of their care. Issues specifically related to farming are also now included, including guidance related to specific farm activities [<https://sites.google.com/site/compendiumofphysicalactivities/Activity-Categories/occupation>, accessed 01/01/15]. The Farm Angina Project highlighted the need for CR to be mindful and not dissociate those using their services *“from their social determinants of health and, crucially, the context of their life”* (Hemingway, 2012, 450). It made me aware that we had to bring aspects of patient's lifeworld in to

rehabilitation in order for our input to be meaningful and positively impactful.

Linked to these strategies Herefordshire CR team is committed to developing “open-heartedness” in their approach to care, in line with the recommendations of Galvin and Todres (2013). That is to develop the skills to attend to people in their differences and otherness, alongside established professional / technical skills. By doing so, enabling them, as individual health professionals, as well as part of a multidisciplinary team, to consider a person’s needs, based on their strengths, in order to help direct care and their vulnerabilities, to know where support is needed. The intention is to create CR that supports individuals with a humanised, lifeworld led approach.

Clark et al. (2012) argue that decisions to attend CR are influenced more by social factors than by health professionals’ advice or clinical information. The authors divide barriers to attendance in to personal and contextual reasons (as detailed in chapter two). Clark et al., (2012, 841) also recommend that family members should feature in any attempt to recruit patients on to CR; *“harness family members to support rather than curtail attendance.”* The Farm Angina Project concurred with many of the findings of this study, related to lack of identification with CR as a service that would be useful to the participant, as a farmer (see Colin’s quote on pages 192-3). Financial and work constraints in tandem with long travel distances were also commonly cited as barriers to attendance. However what Clark et al., (2012) do not consider in their recommendations is, (i) the impact illness has upon other family members and (ii) that family members needs could be incorporated within a more encompassing family-based CR service. Rather, family members are discussed by the authors as if they were passive observers to their relative’s illness, able to support CR intentions when given the nod and without question. Clarke et al (2012) does not acknowledge that other family members may be

suffering from the impact of their relative's illness in an existentially different, yet no less relevant way. The Farm Angina Project reveals this and demonstrates how a couple's potentially differing lifeworld perspectives of illness effects existential wellbeing and subsequently dyadic coping. Although there was no evidence in my study to suggest partners discouraged the men from attending CR, there appeared little encouragement for it either. This study highlights the need to for CR professionals to engage with couples from farming backgrounds individually as well as a dyad, and not just as *'patient and carer'*. Although a caring relationship in *"reciprocity"* has been shown to be beneficial, particularly for partners of ill spouse's, as discussed in chapter nine (Erlington et al., 2012), I would suggest that, based on the findings of the Farm Angina Project, the individual needs of each partner are the initial steps from which relational strategies can then be developed. By doing this we acknowledge each dyad members individual suffering equally. This is in tandem with the findings of Benyamini et al. (2007, 781) who also argue *"the importance of attending to both partners' perceptions when planning interventions aimed at improving recovery from, and adjustment to, illness"*.

As a consequence of this individualised-couple based approach attendance at CR might be improved, because it encourages a sharing of perspectives, vulnerabilities and building of mutual support based on dyads inherent strengths. The CR department is therefore currently designing a partner / family specific support strategy, in line with the findings of the Farm Angina Project, which will run alongside its established practices.

In 2013, I helped to introduce the Herefordshire Cardiac Support Group (www.hcsg.org.uk). This is a peer supported programme organised around evening meetings, daytime community exercise / walks, to help establish a place and space where lifeworld problems can be discussed with others holding similar illness experiences. The support group is

inclusive of patients' families and is now run by a committee of ex-patients.

I plan to publish the results of the Farm Angina Project, locally, through the county's various media channels, e.g. The Hereford Times, Radio Wyvern, etc. I also intend to present findings to attendees of Herefordshire Cardiology's annual study day, which includes all clinicians involved with patient care, in this speciality, as well as local GPs.

Finally, there is a need to consider a dedicated healthcare clinic, located at the new farmers' market, Hereford, which covers not only heart disease, but also other common medical problems, such as diabetes, respiratory problems, psychological issues, musculoskeletal pain / dysfunction, as well as social issues, etc. The utilisation by reluctant farmers of such a clinic has been evidenced, elsewhere (Syson-Nibbs et al., 2006) and is therefore a significant health benefit option worthy of further consideration.

10.5.2 National / International

In Brady's Forward (2009) to the book titled *"Poetic Inquiry: Vibrant Voices in the Social Sciences"*, he argues that poetic methods require self-conscious participation by the reader, thus magnifying the experiences being presented and asking the reader to become involved. I welcome the idea of writing creatively from a secure research base, in such a way that it remains scientifically credible, but at the same time requires the reader's close personal proximity. Galvin and Todres (2013, 160) describe the role of the qualitative researcher as an *"evocative mediator"*, whose poetic writing should create sufficient *"freedom for personal reference"*, so that the reader actively engages with the work and draws from it their own conclusions. The authors argue that reporting which is overly defined and formal does not ask anything of its audience and so can lose its impact: *"as evocative mediators we attempt to offer words that can open up the*

between of intersubjective space" (Galvin and Todres, 2013, 161). To this end, I hope to become an evocative mediator of my work, at national / international level.

I shall continue to support an internet-based presence through the web-page www.farmanginaproject.com, which presents the stories of the study's participants, in an accessible, humanised way, through poetry, composite narratives and photographic images. My intention is that this work continues to resonate personally in some way with those who visit the site. It is also a networking gateway, where opportunities will emerge to share my experiences, reciprocally, as a clinician and researcher.

My intention is to present the findings and recommendations of this study to a national and international audience. I presented the Farm Angina Project at the Institute of Rural Health (IRH) Conference, in 2011. I hope to revisit this group and present my findings, over the next year. I also plan to speak at the British Association for Cardiovascular Prevention and Rehabilitation (BACPR) Conference in 2016. I also intend to submit work for publication, at a number of differing levels. My main aim is to have a paper accepted by a recognised scientific publication, such as The Journal of Rural Studies, by Elsevier, The Journal of Rural Health, by Wiley, or internet-based Electronic Journal of Rural and Remote Health Research (<http://www.rrh.org.au/home/>).

10.6 Reflection: My Transformational Journey

In keeping with a hermeneutic phenomenological approach, my personal development through the different research stages has also become an important facet of the study, as a researcher, but possibly more importantly as a clinician. The words of T.S. Elliot, at the start of this chapter make reference to this journey of exploration and how my view of CR was ultimately changed, where naively I envisaged that only additional tweaks might be necessary. In allowing myself to be submerged by the subject and enter into the swirl that is the

hermeneutic circle, my own experiences ultimately brought to me a sense of “*seeing anew*” that which I already considered known. This may be a well-worn quotation relating to such research, but that is because it sums up so eloquently and succinctly the journey one takes when undertaking hermeneutic phenomenological research; I therefore offer no apology for its use.

In their book, *Transformative Phenomenology*, Rehorick and Bentz (2009, 4) assert that “*the phenomenological lens is more than a lens of understanding. It is a mirror, which allows the phenomenologist to see oneself in a new way*”. I recognised this transition in myself. My practice, my view of how I communicate, share information, and what I believed people with heart disease experienced, needed to know and enact, changed forever. Ultimately, I learnt that it is not just about how we shape CR towards farming couples; it also involves a deeper understanding and undertaking to connect with all patients, in a more caring and meaningful way. It is about how I shape myself. I am drawn towards Rehorick and Bentz (2009, 24)’s articulate summing:

“Phenomenology provides a philosophical and practical framework for cultivating wisdom by challenging researchers and practitioners to look deeply into their subject matter and themselves”.

There is no way back, now this new perspective is with me. I stand in the same place I have for the last seven years; yet, feel I am only now getting to know it. I have a better understanding of how to help farming dyads with SAP through their narratives. I am also changed through my work as a researcher, now as a clinician.

10.7 Summary of the Chapter

Within this chapter I have given a review of the Farm Angina Project and outlined its strengths and limitations. I went on to discuss recommendations for further investigation, based on my research. An outline of this study’s local / national influence was then given, as well

as future intentions related to this research. Finally, I described the transformative power of phenomenology and how, in undertaking the practical elements of this research, my approach to those suffering heart disease, as well as their partners, was changed, for the better.

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“scarf dances away
leaving me mud kneeling -
autumn rusts the farm”



“I did most of the hard physical work of the horses every day, mucking out and everything because he wasn’t meant to push the wheelbarrow or do anything, and then of course when he had his stents he still wasn’t supposed to lift or do anything so I did all the mucking out of the horses, so I got incredibly fitand quite tired sometimes”

Janet

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12.APPENDICES


“frightened to touch
but needing a hand to hold
sex suffers, not love”



“...how have we managed as a couple? Um, it’s not an easy one to answer that. I think emotionally we have coped quite well really. The physical side of our relationship disappeared because one was anxious as to whether you should or shouldn’t, so that vanished...”

Mary

12.1 Appendices A: Ethical Approval

Research & Development		Herefordshire  Primary Care Trust
		Research & Development C/o Worcestershire Acute Hospitals NHS Trust Clinical Research Unit Newtown Road Worcester WR6 1DD Tel: 01905 760221 Fax: 01905 760262
17 th December 2010		
Stephen Heptinstall Cardiac Rehabilitation Practitioner Hereford County Hospital Union Walk Hereford HR1 2ER		
Dear Stephen,		
Re: How Do Farming Couples Experience Angina Pectoris? A Phenomenological Study.		
MREC: 10/H1202/53	R&D: HCH140610	
I am pleased to inform you that the R&D review of the above project is complete and has been formally approved to be undertaken at Herefordshire Primary Care Trust . Your research activity is now covered by NHS indemnity as set out in HSG (96) 48 and your trial has now been entered onto the trust's database.		
The following documents were reviewed:		
Protocol Version 6 dated 8 th June 2010 Participant Information Sheet Version 7 dated 26 th July 2010 Participant Consent Form Version 7 dated 26 th July 2010 Support Information Sheet Version 6 dated 8 th June 2010 Interview Schedules Version 6 dated 8 th June 2010 NRES Letter dated 6 th September 2010 NRES Letter dated 8 th July 2010 NRES Letter dated 15 th June 2010 Insurance Certificate (ACN) dated 27 th September 2010 Insurance Certificate (Zurich) dated 20 th July 2010 Letter of Sponsorship dated 8 th June 2010 CV for PI/CI Stephen Heptinstall NHS Form lock code 14704/174744/6/818/90617/200316 NHS REC Form lock code 14704/126554/1/152		
Your responsibilities are set out in the attached agreement, which must be signed and returned to the R&D Office. You should keep a copy for your records.		
All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF) and to ICH-GCP standards. In order to ensure that		

research is carried out to these standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time and you must co-operate with the auditors.

The duration of Trust approval extends to the date specified in the NRES application form. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors. Research must commence within two years of the REC approval date, and within six months of R&D approval.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely,

A handwritten signature in blue ink, appearing to read 'Thomas Llewellyn', with a long horizontal flourish extending to the right.

Thomas Llewellyn
R&D Facilitator

Enc: PI Agreement

Research & Development

West Midlands (South) Comprehensive Local Research Network
Fourth Floor, West Wing (ACF40002)
University Hospitals Coventry & Warwickshire NHS Trust
University Hospital
Clifford Bridge Road
Coventry
CV2 2DX

2nd November 2010

Stephen Heptinstall
Cardiac Rehabilitation Practitioner
Hereford County Hospital
Union Walk
Hereford
HR1 2ER

Dear Mr Heptinstall

**Project Title: How Do Farming Couples Experience Angina Pectoris? A
Phenomenological Study.**
R&D Ref: HCH140610
REC Ref: 10/H1202/53

I am pleased to inform you that the R&D review of the above project is complete, and the project has been formally approved to be undertaken at Hereford Hospitals NHS Trust. Your research activity is now covered by NHS indemnity as set out in HSG (96) 48, and your trial has been entered onto the Trust's database.

The following documents were reviewed:

- Protocol Version 6 dated 8th June 2010
- Participant Information Sheet Version 7 dated 26th July 2010
- Participant Consent Form Version 7 dated 26th July 2010
- Support Information Sheet Version 6 dated 8th June 2010
- Interview Schedules Version 6 dated 8th June 2010
- NRES Letter dated 6th September 2010
- NRES Letter dated 8th July 2010
- NRES Letter dated 15th June 2010
- Insurance Certificate (AON) dated 27th September 2010
- Insurance Certificate (Zurich) dated 30th July 2010
- Letter of Sponsorship dated 8th June 2010
- CV for PI / CI Stephen Heptinstall
- NHS SSI Form lock code 14704/126798/6/786/62357/179414 signed and dated 9th June 2010
- NHS REC Form lock code 14704/126554/1/152 signed and dated 8th June 2010
- NHS Form A (Hereford R&D Committee) signed and dated 2nd August 2010

Your responsibilities are set out in the attached agreement, which must be signed and returned to the R&D Office. You should keep a copy for your records.

All research must be managed in accordance with the requirements of the Department of Health's Research Governance Framework (RGF) and to ICH-GCP standards. In order to ensure that research is carried out to these standards, the Trust employs the services of an external monitoring organisation to provide assurance. Your study may be randomly selected for audit at any time, and you must co-operate with the auditors.

The duration of Trust approval extends to the date specified in the R&D application form. Action may be taken to suspend Trust approval if the research is not run in accordance with RGF or ICH-GCP standards, or following recommendations from the auditors. Research must commence within two years of the REC approval date and within six months of NHS Permission.

I wish you well with your project. Please do not hesitate to contact me should you need any guidance or assistance.

Yours sincerely

A handwritten signature in blue ink, appearing to read 'T. Llewellyn', with a long horizontal flourish extending to the right.

Thomas Llewellyn
R&D Facilitator

Enc: PI Agreement

12.2 Appendix B: Participant Information Sheet

ARE YOU A FARMER OR FARM WORKER? ARE YOU THE PARTNER OF A FARMER OR FARM WORKER?

If you are please read this:

**We are undertaking a research study entitled
'How do farming couples experience angina pectoris?'
and are looking for farming couples to take part in this
research.**

This Information Sheet tells you the purpose of the study and what will happen to you if you take part. If there is anything that is not clear, if you would like more information, or if you and your partner wish to be considered for this study please contact me:

Stephen Heptinstall, Chief Researcher Tel: 01432 364206

What is the purpose of the study?

The aim of the study is to better understand farmers and their partners' experiences of newly diagnosed angina pectoris; what the impact of this disease is for each of them and how they manage it individually and as a couple.

Why have I been given this information?

You have been given this information because you are attending the Rapid Access Chest Pain Clinic and/or Angiography at Hereford County Hospital. During this visit you may have received a diagnosis of angina pectoris; this is the first requirement of the study. You

must also be a farmer/farm-worker or the partner of a farmer/farm-worker to be able to participate.

What does the study involve?

The study involves a series of interviews with you and your partner (preferably separately) to find out how angina affects your lives.

Each interview will be for approximately 1 hour, on three occasions, over 12-months.

Interviews will be held in your home or at Hereford County Hospital, whichever venue you prefer, at a time that is convenient for you both. Each interview will be recorded so that what you say can be analysed later. This will help us to build up a picture of your experiences and compare these to others in similar circumstances.

Do I have to take part?

It is up to you to decide whether or not to take part. It is also up to your partner in the same way. The study requires both of you to agree to take part to be included. If you decide to take part you and your partner are still free to withdraw at any time and without giving a reason - this will not affect the standard of care you or your partner receives. Any information obtained from you after consent and up to your decision not to take part will be retained and may be used in the study.

**PLEASE NOTE: You must contact me directly if you wish to participate in the study – Stephen Heptinstall, Chief Researcher
Tel: 01432 364206.**

What reimbursement is there for taking part?

Reimbursement for expenses incurred through participation in the study will be made up to £10 per hour. This includes loss of earnings, travel expenses, child care etc.

What are the possible risks and disadvantages of taking part?

Taking part will not affect you/your partner's treatment or angina in any way.

I am not aware of any disadvantages to you by taking part in the study. However, our discussions may cause some people distress due to the subject matter. If at any time you get upset, I will offer to pause or stop the interview. Service Information Sheets will also be available to any participant who feels they require further support after considering their situation during these discussions. A named cardiac rehabilitation clinical nurse specialist will also be available to offer timely professional support.

What are the possible benefits of taking part?

There are no specific advantages to you in taking part, although what you tell me may benefit you and other patients in the future by helping to improve our understanding of farming couples' experiences of angina pectoris. The Cardiac Rehabilitation department at Hereford County Hospital hopes to use the information gained by the study to introduce an angina management programme that is sensitive to the needs of the farming community.

Will my taking part in this study be kept confidential?

All information about you that is collected during the course of this research will be kept strictly confidential. It will only be shared with members of the research team and the studies' academic supervisors. Any information about you that leaves the hospital will have your name and address removed so that you cannot be recognised from it. All names and places mentioned during our discussions will also be changed so that you cannot be identified through association with such information.

The recordings of our discussions and subsequent transcripts will be kept secure in a locked filing cabinet, within Cardiac Rehabilitation, based at Hereford County Hospital. Electronic copies of our discussions will be saved on a secure computer, maintained by

Hereford County Hospital, accessible through coded entry, known only to the Chief Researcher. At the end of the study all recordings will be destroyed.

What if there is a problem?

You can contact me if you have any concerns about the way you have been approached or treated during the course of this study. If you wish to discuss any issues with someone other than me, you may contact the Patient Advisory Liaison (PALS) office, based at Hereford County Hospital Tel: 01432 372986.

What will happen to the results of the research study?

What you tell us will be used to undertake a second round of research in which health professionals will be invited to consider how they might best serve the needs of angina sufferers and their partners from a farming community. The results of both studies will be published as a full report, research papers in academic and professional journals and presented at conferences. At the end of both studies a summary of the results will be sent to you and your partner if you would like to receive them.

Who is organising and funding the research?

The study is being organised by me, as part of a higher research degree (MPhil/PhD) through the Psychology Department at the University of Bath.

Who has reviewed the study?

The design of the study has been reviewed by Dr P. Smith and Dr H. Lucey from the University of Bath. The West Midlands Regional Ethics and local Herefordshire NHS Research & Development Committees have also given permission for the study to be undertaken.

Contact for further information

If you and your partner wish to be considered for this study and/or have further questions please contact me:

**Stephen Heptinstall MSc MCSP, Chief Researcher,
Cardiac Rehabilitation, The Old Chapel, Fred Bulmer Building,
Hereford County Hospital, HR1 2ER - Telephone/fax: 01432
364206**

If you wish to obtain impartial general information regarding taking part in NHS research you can contact the following: **Amanda Jones, R&D Manager Tel: 01905 760221**

Thank you for taking the time to read this information sheet

12.3 Appendix C: Participant Support Sheet 9 (Extract)



Hereford Hospitals
NHS Trust



PARTICIPANT SUPPORT SHEET

These sheets contain a list of support services available to you in Herefordshire.

Should you have any issues or concerns about the way you are being treated as part of the Farm Angina Project please discuss these with the Chief Researcher, Steve Heptinstall on Tel: 01432 364206.

Anne Marie Scott, Cardiac Rehabilitation Clinical Nurse Specialist is also available to discuss any support issues related to your angina. She can also be reached on Tel: 01432 364206.

You can also contact the Patient Advisory and Liaison Service (PALS) based at Hereford County Hospital. PALS aims to (1) Advise and support patients, their families and carers; (2) Provide information on NHS services; (3) Listen to your concerns, suggestions and queries (4) Help sort out problems quickly on your behalf. Tel: 01432 372986.



Further details of all Cardiac Services and the PALS service are available on line at www.herefordhospitals.nhs.uk.

Below is a list of support services available within Herefordshire:

Support:	Area:	Place name:	Organisation:	Type:	Address:			Tel:	Web:
Welfare	Central	Newton Farm Information Centre	Citizens Advice Bureau	Charity	23 The Oval	Hereford		01432 279116	herefordshirecab.org.uk
Welfare	Central	Hollybush Family Centre	Citizens Advice Bureau	Charity	8 St Owen St	Hereford	HR1 2PJ	0870 1264091	herefordshirecab.org.uk
Welfare	East	Bromyard Centre	Citizens Advice Bureau	Charity	Croxwell St	Bromyard	HR7 4EB	0870 1264091	herefordshirecab.org.uk
Welfare	North	47 Duke Street	Citizens Advice Bureau	Charity	47 Duke St	Kington	HR5 3DR	0870 1264091	herefordshirecab.org.uk
Welfare	North	Info in Herefordshire	Citizens Advice Bureau	Charity	11 Corn Square	Leominster	HR6 8LR	0870 1264091	herefordshirecab.org.uk

Welfare	North	St Catherine's House	Citizens Advice Bureau	Charity	1st Floor St Catherine's House	Ledbury	HR8 1EA	0870 1264091	herefordshirecab.org.uk
Welfare	North	Ryefield Centre	Citizens Advice Bureau	Charity	Grammar School Close	Ross-On-Wye	HR9 7QD	0870 1264091	herefordshirecab.org.uk
Welfare	North	Telephone	Citizens Advice Bureau	Charity	8 St Owen St	Hereford	HR1 2PJ	01432 377 599	herefordshirecab.org.uk
Welfare	County	The Warehouse	ABLE	Charity	Conningsby St	Hereford	HR1 2DY	01432 356626	
Welfare	Central	Blackfriars St	Parent Partnership Service	Council	Blackfirars St	Hereford	HR4 9ZR	01432 260955	
Welfare	County	Block A	Inland Revenue	Council	Wittington Road	Worcester	WR5 2LE	0845 302 1482	hmrc.gov.uk
Welfare	County	Block A	Inland Revenue	Council	Wittington Road	Worcester	WR5 2LE	0845 302 1482	hmrc.gov.uk
Welfare	County	Advocacy House	Herefordshire People's Advocacy Service	Charity	103-104 East St	Hereford	HR1 2LW	01432 263757	
Welfare	County	Mortimer House	Herefordshire Carers Support	Charity	Holmer Road	Hereford	HR4 9TA	01432 356068	
Welfare	County	92b Widemarsh St	Carers Action	Charity	92b Widemarsh St	Hereford	HR4 9HG	01432 272724	carersaction.org.uk
Welfare	North	INFO The Kington Centre	Herefordshire Council	Council	64 Bridge St	Kington			herefordshire.gov.uk
Welfare	East	5 Broad St	Age Concern	Charity	5 Broad St	Bromyard	HR7 4BS	01885 483483	achw.org.uk
Welfare	East	38 Bye St	Age Concern	Charity	38 Bye St	Ledbury	HR8 2AA	01531 631280	achw.org.uk
Welfare	North	30 West St	Age Concern	Charity	30 West St	Leominster	HR6 8ES	01568 611054	achw.org.uk
Welfare	South	The Ryefield Centre	Age Concern	Charity	Grammar School Close	Ross-On-Wye	HR9 7QD	01989 567165	achw.org.uk
Welfare	West	14 High St	Builth Wells Community Support	Charity	Builth Wells	Powys	LD2 3DN	01982 553004	
Welfare	Central	Heffernan House	MIND	Charity	130/132 Widemarsh St	Hereford	HR4 9HG	01432 357523	mind.org.uk
Welfare	Central	Stonebow Psychiatric Unit	MIND	Charity	Stonebow Road	Hereford	HR1 2BN	01432 357523	mind.org.uk
Welfare	North	The Vergers House	MIND	Charity	The Priory	Leominster		01432 357523	mind.org.uk
Welfare	East	Ledbury Centre	MIND	Charity	Leadon Bank	Ledbury	HR8 1DQ	01432 357523	mind.org.uk
Welfare	County	Head Office	Herefordshire Careline	Charity	Legion Way	Hereford	HR1 1LN	01432 384100	hhl.org.uk
Welfare	County	Telephone	Residents and Relatives Assoc	Charity	6-18 Northampton St	London	N1 2HY	020 7359 8136	relres.org
Welfare	County	Internet	Help The Aged	Charity	207-221 Pentonville Road	London	N1 9UZ	020 7218 1114	helptheaged.org.uk
Welfare	County	Internet	Mencap	Charity	123 Golden Lane	London	EC1Y ORT	020 7454 0454	mencap.org.uk
Welfare	County	Telephone/Internet	Patient Concern	Charity	P.O. Box 23732	London	SW5 9FY		patientconcern.org.uk
Welfare	County	Telephone/Internet	Turning Point	Charity	Standon House	London	E1 8AA	020 7841 7600	turning-point.co.uk
Welfare	County	Telephone/Internet	SCOPE	Charity	P.O. Box 834	Milton Keynes	MK12 5NY	0808 800 3333	scope.org.uk
Welfare	County	Telephone/Internet	SENSE	Charity	9a Birkdale Avenue	Birmingham	B29 6UG	0121 415 2720	sense.org.uk

12.4 Appendix D: Participant Consent Form

	Hereford Hospitals NHS Trust	
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Consent Form

Study Title:

How do farming couples experience angina pectoris? A Qualitative Study

Chief Researcher Details:

Stephen Heptinstall MSc. MCSP

c/o The Cardiac Rehabilitation Department, The Old Chapel, Fred Bulmer Building,
Hereford County Hospital, Union Walk, Hereford, Herefordshire HR1 2ER

Telephone/Fax: 01432 364206

Consent: **Please tick each box**

1. I confirm that I have read and understand the Information Sheet, dated 08/06/10 (version 6) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without this affecting my medical care, my legal rights, or those of my partner. ☐

3. I agree that anything I may say during the course of the interview may be used as anonymous quotes in any presentation of the research (verbal presentation, paper publication or teaching purposes) ☐

4. I agree to allow my interviews to be recorded using a digital sound recording device. I understand I can halt recording at any time or decide not to allow further recording to take place. ☐

5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Researcher	Date	Signature

One copy given to the participant, one copy retained by the researcher ☐

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12.5 Appendix E: Interview Schedules

Male Angina Sufferer Farmer Interview Schedule

Angina Client 1st Interview Schedule

Name:	
DOB:	
ID number:	

Main role:	
Farm type:	
Other employment:	

Interview date:	
Duration:	
Venue:	

Introduction

First of all I would like to thank you for taking the time to talk to me. As you know we are interested in understanding your experience of being diagnosed and living with angina, so there are no right or wrong answers. I have here some topics which might be useful to discuss, but most important are your experiences.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential. I am not going to talk to anyone about what we discuss, other than the research team and my university supervisor. Your name will not be mentioned in any reports arising from this study.

PART ONE: FARMING
1. Firstly I would like to know a little bit more about your work. How did you come to be a farmer?
<i>Prompt: Are you from a long line of farmers?</i> <i>Prompt: How do you feel about being a farmer?</i>
2. What does your job involve at this time of the year?
<i>Prompt: Is it a particularly busy time?</i> <i>Prompt: Is it a stressful time? If Yes – why?</i>

<p><i>Prompt: Do you feel isolated presently from others because of the work you do? Why/why not?</i></p>
<p>3. How do you relax away from work?</p>
<p><i>Prompt: Do you have any hobbies, pastimes? Are you a member of a local group, church? Any other duties outside farming?</i> <i>Prompt: Do you have any difficulty in getting away from work or being able to relax?</i></p>
<p>PART TWO: ANGINA EXPERIENCE</p>
<p>4. Please tell me about the first time you noticed your angina?</p>
<p><i>Prompt: How long ago? What were you doing? What did you do? Ignore/get help?</i> <i>Prompt: Was it linked to stress, increased physical labour, financial worries?</i> <i>Prompt: What help did you receive?</i> <i>Prompt: What do you know about angina?</i></p>
<p>5. How does angina affect you now?</p>
<p><i>Prompt: Does your angina affect the way you do things on the farm? Why? i.e. is it a particularly stressful time? Does it involve a lot of physical labour?</i> <i>Prompt: How does your angina affect you socially?</i> <i>Prompt: How does your angina affect your relations with other family members?</i> <i>Prompt: What is the biggest impact angina has had upon your lifestyle?</i></p>
<p>6. How does this make you feel?</p>
<p><i>Prompt: Does having angina affect your mood? i.e. anxious, depressed, stressed</i> <i>Prompt: How do you deal with this aspect of your angina?</i></p>
<p>7. How are you presently supported?</p>
<p><i>Prompt: On the farm? Family/partner, friends, employees?</i> <i>Prompt: Other aspects of life? i.e. emotionally, socially? By whom?</i> <i>Prompt: With regards to your health i.e. GP, Practice Nurse etc...</i> <i>Prompt: How do you feel about accepting support? Angry? Pleased? Have you refused any? If so, why did you?</i></p>
<p>8. Describe how you see the future?</p>
<p><i>Prompt: From a health perspective?</i> <i>Prompt: Regarding the farm and your role within it?</i> <i>Prompt: Do you have any particular worries or concerns?</i></p>
<p>9. Is there anything else you would like to tell me?</p>

That concludes our first interview. Thank you for taking part.

As I said at the start all that we have discussed will be kept confidential. If you have any more questions or concerns I would be happy to discuss them now or you can ring me later on the telephone number I have already provided.

We need to meet on two more occasions over the next year. Our next meeting will be 6 months time, at a time and date that is convenient for you. I will write and then ring you to discuss this nearer the time.

Angina Client 2nd Interview Schedule

Introduction

First of all I would like to thank you for taking the time to talk to me. As you know we are interested in understanding your experience of being diagnosed and living with angina, so there are no right or wrong answers. I have here some topics which might be useful to discuss, but most important are your experiences. The format is just the same as the first time we met.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential. I am not going to talk to anyone about what we discuss, other than the research team and my university supervisor. Your name will not be mentioned in any reports arising from this study.

NB: During follow up interviews questions will be iterative. Some degree of flexibility will be incorporated to follow any particular themes identified during the first interview.

ANGINA CLIENT 2 ND INTERVIEW SCHEDULE	
1. How have you been since our last meeting?	
<p><i>Prompt: How has your health been? Related to your angina?</i></p> <p><i>Prompt: If bad, How has this impacted upon you? Physically, mentally, re: activity</i></p> <p><i>Prompt: What affect has this had on relationships?</i></p> <p><i>Prompt: How have you managed this? What have you changed, how have you relaxed?</i></p>	
2. What does your work on the farm involve at this time of the year?	
<p><i>Prompt: Is it a particularly busy time?</i></p> <p><i>Prompt: Is it a stressful time? If Yes – why?</i></p> <p><i>Prompt: Do you feel isolated presently from others because of the work you do? Why/why not?</i></p>	
3. How does angina affect you now?	
<p><i>Prompt: Does your angina affect the way you do things on the farm? Why? i.e. Is it a particularly stressful time? Does it involve a lot of physical labour?</i></p>	

<i>Prompt: How does your angina affect you socially?</i> <i>Prompt: How does your angina affect your relations with other family members?</i> <i>Prompt: What is the biggest impact angina has had upon your lifestyle?</i>
4. How does this make you feel?
<i>Prompt: Does having angina affect your mood? i.e. anxious, depressed, stressed</i> <i>Prompt: How do you deal with this aspect of your angina?</i>
5. How are you presently supported?
<i>Prompt: On the farm? Family/partner, friends, employees?</i> <i>Prompt: Other aspects of life? i.e. emotionally, socially?</i> <i>Prompt: With regards to your health i.e. GP, Practice Nurse etc...</i> <i>Prompt: How do you feel about accepting support? Angry? Pleased? Have you refused any? If so, why did you?</i>
6. Describe how you see the future?
<i>Prompt: From a health perspective?</i> <i>Prompt: Regarding the farm and your role within it?</i> <i>Prompt: Do you have any particular worries or concerns?</i>
7. Is there anything else you would like to tell me?

That concludes our second interview. Thank you for taking part.

As I said at the start all that we have discussed will be kept confidential. If you have any more questions or concerns I would be happy to discuss them now or you can ring me later on the telephone number I have already provided.

We need to meet on one more occasion. Our next meeting will be 6 months' time, at a time and date that is convenient for you. I will write and then ring you to discuss this nearer the time.

Angina Client 3rd Interview Schedule

Introduction

First of all I would like to thank you for taking the time to talk to me. As you know we are interested in understanding your experience of being diagnosed and living with angina, so there are no right or wrong answers. I have here some topics which might be useful to discuss, but most important are your experiences. The format is just the same as the first time we met.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential. I am not going to talk to anyone about what we discuss, other than the research team and my university supervisor. Your name will not be mentioned in any reports arising from this study.

NB: During follow up interviews questions will be iterative. Some degree of flexibility will be incorporated to follow any particular themes identified during the first interview.

ANGINA CLIENT 3 rd INTERVIEW SCHEDULE
1. How have you been since our last meeting?
<p><i>Prompt: How has your health been? Related to your angina?</i> <i>Prompt: If bad, How has this impacted upon you? Physically, mentally, re: activity</i> <i>Prompt: What affect has this had on relationships?</i> <i>Prompt: How have you managed this? What have you changed, how have you relaxed?</i></p>
2. What does your work on the farm involve at this time of the year?
<p><i>Prompt: Is it a particularly busy time?</i> <i>Prompt: Is it a stressful time? If Yes – why?</i> <i>Prompt: Do you feel isolated presently from others because of the work you do? Why/why not?</i></p>
3. How does angina affect you now?
<p><i>Prompt: Does your angina affect the way you do things on the farm? Why? i.e. Is it a particularly stressful time? Does it involve a lot of physical labour?</i> <i>Prompt: How does your angina affect you socially?</i> <i>Prompt: How does your angina affect your relations with other family members?</i> <i>Prompt: What is the biggest impact angina has had upon your lifestyle?</i></p>
4. How does this make you feel?
<p><i>Prompt: Does having angina affect your mood? i.e. anxious, depressed, stressed</i> <i>Prompt: How do you deal with this aspect of your angina?</i></p>
5. How are you presently supported?
<p><i>Prompt: On the farm? Family/partner, friends, employees?</i> <i>Prompt: Other aspects of life? I.e. emotionally, socially?</i> <i>Prompt: With regards to your health i.e. GP, Practice Nurse etc...</i> <i>Prompt: How do you feel about accepting support? Angry? Pleased? Have you refused any? If so, why did you?</i></p>
6. Describe how you see the future?
<p><i>Prompt: From a health perspective?</i> <i>Prompt: Regarding the farm and your role within it?</i> <i>Prompt: Do you have any particular worries or concerns?</i></p>

7. This is our last interview. Looking back over the last year is there anything else important about your experiences that you would like to share?
<i>Prompt: Effect on life? Work? Relationships?</i> <i>Prompt: How you have dealt with it? What worked, what didn't?</i> <i>Prompt: Any advice for others who may go through similar?</i> <i>Prompt: Any advice for health professionals such as myself?</i>
8. Is there anything else you would like to tell me?

That concludes our third and final interview. Thank you for taking part.

As I said at the start all that we have discussed will be kept confidential. If you have any more questions or concerns I would be happy to discuss them now or you can ring me later on the telephone number I have already provided.

All we have discussed over the last year will be analysed and featured in a final report that I will send to you if wish for me to do so.

Female Partner Interview Schedules

Partner 1ST Interview Schedule

Name:	
DOB:	
ID number:	

Main role:	
Farm type:	
Other employment:	

Interview date:	
Duration:	
Venue:	

Introduction

First of all I would like to thank you for taking the time to talk to me. As you know we are interested in understanding your experiences of living with someone who has been diagnosed angina, so there are no right or wrong answers. I have here some topics which might be useful to discuss, but most important are your experiences.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential. I am not

going to talk to anyone about what we discuss, other than the research team and my university supervisor. Your name will not be mentioned in any reports arising from this study.

PART ONE: FARMING
1. Firstly I would like to know a little bit more about your background. How did you come to be involved with farming?
<i>Prompt: Through marriage? Are you from a farming family?</i>
2. In what ways are you involved with the farm?
<i>Prompt: Active on the farm - All the time or when it is a particularly busy time?</i> <i>Prompt: In the home - As a wife and/or mother?</i> <i>Prompt: Do you work anywhere else? If so, why?</i> <i>Prompt: Is the balance between home and work stressful? If Yes – why?</i> <i>Prompt: Do you feel isolated because by your lifestyle? Why/why not?</i>
3. How do you relax away from work?
<i>Prompt: Do you have any hobbies, pastimes? Are you a member of a local group, church? Any other duties outside farming?</i> <i>Prompt: Do you have any difficulty in getting away from work or being able to relax?</i>
PART TWO: ANGINA EXPERIENCE
4. Please tell me about the first time you noticed your partner's angina?
<i>Prompt: How long ago? What were you doing? What did you do? Ignore/get help?</i> <i>Prompt: Was it linked to stress, increased physical labour, financial worries?</i> <i>Prompt: What help did you receive?</i> <i>Prompt: What do you know about angina?</i>
5. How is your partners' angina at the moment? How does their angina affect you?
<i>Prompt: Does your partner's angina affect the way you do things? On the farm? In the home? Out socially?</i> <i>Prompt: How does their angina affect relations with you and other family members?</i>
6. How does this make you feel?
<i>Prompt: Does your partner having angina affect your mood? I.e. anxious, depressed, stressed. How do you deal with this?</i>

7. How are you presently supported?
<i>Prompt: Family/partner, friends, employees?</i> <i>Prompt: Do you have a particular confidante?</i> <i>Prompt: Other aspects of life? I.e. emotionally, socially? By whom?</i> <i>Prompt: How do you feel about accepting support? Angry? Pleased? Have you refused any? If so, why did you?</i>
8. Describe how you see the future?
<i>Prompt: From a health perspective for you and your partner?</i> <i>Prompt: Regarding the farm and your role within it?</i> <i>Prompt: With regards to family?</i> <i>Prompt: Do you have any particular worries or concerns?</i>
9. Is there anything else you would like to tell me?

That concludes our first interview. Thank you for taking part.

As I said at the start all that we have discussed will be kept confidential. If you have any more questions or concerns I would be happy to discuss them now or you can ring me later on the telephone number I have already provided.

We need to meet on two more occasions over the next year. Our next meeting will be 6 months' time, at a time and date that is convenient for you. I will write and then ring you to discuss this nearer the time.

Partner 2nd Interview Schedule

Introduction

First of all I would like to thank you for taking the time to talk to me. As you know we are interested in understanding your experience of living with someone with angina, so there are no right or wrong answers. I have here some topics which might be useful to discuss, but most important are your experiences. The format is just the same as the first time we met.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential. I am not going to talk to anyone about what we discuss, other than the research team and my university supervisor. Your name will not be mentioned in any reports arising from this study.

NB: During follow up interviews questions will be iterative. Some degree of flexibility will be incorporated to follow any particular themes identified during the first interview.

PARTNER 2ND INTERVIEW SCHEDULE

1. How have you been since our last meeting?
<p><i>Prompt: How has your health been? Physically, psychologically?</i></p> <p><i>Prompt: If bad, why and how has this impacted upon you?</i></p> <p><i>Prompt: What affect has this had on your relationship with your partner?</i></p> <p><i>Prompt: How have you managed this?</i></p>
2. What are you involved with at the moment?
<p><i>Prompt: Work on the farm, in the home, both?</i></p> <p><i>Prompt: Is your work stressful at this present time?</i></p> <p><i>Prompt: Other duties – to family, relatives, and friends?</i></p> <p><i>Prompt: How do you relax? Any hobbies, social clubs, church, other...</i></p>
3. How is your partner at the moment? How does it affect you?
<p><i>Prompt: Does their angina affect the way you do things on the farm?</i></p> <p><i>Prompt: How does their angina affect you socially?</i></p> <p><i>Prompt: How does their angina affect relations with you and other family members?</i></p>
4. How does this make you feel?
<p><i>Prompt: Does their condition make you feel anxious, depressed, stressed?</i></p> <p><i>Prompt: How do you deal with this?</i></p>
5. How are you presently supported?
<p><i>Prompt: Family/partner, friends, employees?</i></p> <p><i>Prompt: Do you have a particular confidante?</i></p> <p><i>Prompt: Regarding other aspects of life? I.e. emotionally, socially?</i></p> <p><i>Prompt: How do you feel about accepting support? Angry? Pleased? Have you refused any? If so, why did you?</i></p>
6. Describe how you see the future?
<p><i>Prompt: From a health perspective for you and your partner?</i></p> <p><i>Prompt: Regarding the farm and your role within it?</i></p> <p><i>Prompt: Regarding the family?</i></p> <p><i>Prompt: Do you have any particular worries or concerns?</i></p>
7. Is there anything else you would like to tell me?

That concludes our second interview. Thank you for taking part.

As I said at the start all that we have discussed will be kept confidential. If you have any more questions or concerns I would be happy to discuss them now or you can ring me later on the telephone number I have already provided.

We need to meet on one more occasion. Our next meeting will be 6 months' time, at a time and date that is convenient for you. I will write and then ring you to discuss this nearer the time.

Partner 3rd Interview Schedule

Introduction

First of all I would like to thank you for taking the time to talk to me. As you know we are interested in understanding your experience of living with someone with angina, so there are no right or wrong answers. I have here some topics which might be useful to discuss, but most important are your experiences. The format is just the same as the first time we met.

I am going to record the interview so that I can listen to what you have said at a later date. However, if you want to stop the interview or the tape recorder at any time you can. All the information you provide will be strictly confidential. I am not going to talk to anyone about what we discuss, other than the research team and my university supervisor. Your name will not be mentioned in any reports arising from this study.

NB: During follow up interviews questions will be iterative. Some degree of flexibility will be incorporated to follow any particular themes identified during the first interview.

PARTNER 3 rd INTERVIEW SCHEDULE	
1. How have you been since our last meeting?	
<i>Prompt: How has your health been? Physically, psychologically?</i> <i>Prompt: If bad, why and how has this impacted upon you?</i> <i>Prompt: What affect has this had on your relationship with your partner?</i> <i>Prompt: How have you managed this?</i>	
2. What are you involved with at the moment?	
<i>Prompt: Work on the farm, in the home, both?</i> <i>Prompt: Is your work stressful at this present time?</i> <i>Prompt: Other duties – to family, relatives, and friends?</i> <i>Prompt: How do you relax? Any hobbies, social clubs, church, other...</i>	
3. How is your partner at the moment? How does it affect you?	
<i>Prompt: Does their angina affect the way you do things?</i> <i>Prompt: How does their angina affect you socially?</i> <i>Prompt: How does their angina affect relations with you and other family members?</i>	
4. How does this make you feel?	

<p><i>Prompt: Does their condition make you feel anxious, depressed, stressed?</i></p> <p><i>Prompt: How do you deal with this?</i></p>
<p>5. How are you presently supported?</p>
<p><i>Prompt: Family/partner, friends, employees?</i></p> <p><i>Prompt: Do you have a particular confidante?</i></p> <p><i>Prompt: Regarding other aspects of life? I.e. emotionally, socially?</i></p> <p><i>Prompt: How do you feel about accepting support? Angry? Pleased? Have you refused any? If so, why did you?</i></p>
<p>6. Describe how you see the future?</p>
<p><i>Prompt: From a health perspective for you and your partner?</i></p> <p><i>Prompt: Regarding the farm and your role within it?</i></p> <p><i>Prompt: Regarding the family?</i></p> <p><i>Prompt: Do you have any particular worries or concerns?</i></p>
<p>7. This is our last interview. Looking back over the last year is there anything else you feel is important about your experiences that you would like to share?</p>
<p><i>Prompt: Effect on life? Work? Relationships?</i></p> <p><i>Prompt: How you have dealt with your partner's condition? What worked, what didn't?</i></p> <p><i>Prompt: Any advice for others who may go through similar?</i></p> <p><i>Prompt: Any advice for health professionals such as myself?</i></p>
<p>8. Is there anything else you would like to tell me?</p>

That concludes our third and final interview. Thank you for taking part.

As I said at the start all that we have discussed will be kept confidential. If you have any more questions or concerns I would be happy to discuss them now or you can ring me later on the telephone number I have already provided.

All we have discussed over the last year will be analysed and featured in a final report that I will send to you if wish for me to do so.

12.6 Appendix F: Narrative Analysis Template (Extract)

EMBODIED MEMO Important field notes, descriptions/ reflections by researcher	INITIAL CODING: IN-VIVO R = Researcher speaking <i>Important in-vivo theme in italic and underlined</i>	INITIAL CODING: DESCRIPTIVE	SECONDARY CODING: INTERPRETATIVE From memo and initial coding
<p>It is my first interview with the partner of a farmer and I am a little nervous. She is also close to my own age which is disconcerting. We are sat in her living room, each on a sofa with a table between. It is mid-afternoon but cold outside.</p> <p>1/4 – Seems pleased to have no responsibilities on the farm</p> <p>1/8 – Says yes and then contradicts herself. Seems uncomfortable to admit it may be - ?guilt</p>	<ol style="list-style-type: none"> R: Erm right, firstly I want to know a little bit about your background, so how did you to become involved with farming? B: Erm <i>just by marrying Jacob 21 years ago. I wasn't at all to do with farming</i>, erm, my dad is an Accountant or was, and erm my mums a teacher and we moved here they moved here ooh about 1985 and they live just rounds the corner and that's how I met, I just went to an after-wedding and erm he was there and that's it. R: Do you have any responsibilities on the farm? B: No, none at all, I teach, and that takes up most of my time, er I occasionally help to move cattle but we haven't got any at the moment, so erm, that's that really I don't do an awful lot, no. R: How do you find the interface between living on a farm that is working and going out to teach? B: Erm I think it's quite a good thing for me, erm, because I erm, I have a journey I need to do to my place of work and, they are very separate, my work and my home life. Erm, having said that, I live on my livelihood, or our livelihood, which I think is, is em, I've never done that before, erm, you know, so it is always a around us what is going on the farm erm but <u>my responsibilities are very much separate to it.</u> R: Okay. Do you, is, is, so is it just to reiterate you feel that your home-work life there is a good balance between the two? B: Well, er...yes but em, teaching encroaches on my home life, so, you know I work most evenings, I've got Jacking, in front of me, I do a lot of work outside my teaching hours as well, so I – I do bring a lot of work home. 	<p>1/2 – Married into farming, with no previous experience or family background</p> <p>1/4 – No responsibilities on the farm presently. Job as teacher takes up most of her time</p> <p>1/6 – Enjoys having a separate work life to home life – A</p> <p>1/6 – Responsibilities are separate to farm</p> <p>1/8 – Feels her teaching role encroaches on her home life.</p>	<p>1/4 – Feels separate to workings of farm</p> <p>1/6 – Enjoys freedom work gives her off the farm. Also monetary gain – which drives lifestyle</p> <p>1/6 – No responsibilities on farm = no pressure from it</p> <p>1/8 – Work role impinges on home role. Likes the former and reluctant to sacrifice for the latter but possibly guilt edged!</p>

	<p>17. R: Over what time period just to get a perspective?</p> <p>18. B: Well he went in on his birthday which was the Tuesday they, we were in there for about three or four hours, they did all the blood tests, we waited for the tests back, test were fine and we came home, but he still had this dullish ache, erm, I just got the impression it wasn't as bad as it had been, it was the, Tuesday we were back, Wednesday he carried on, Thursday he carried on, forget when we finished now, <u>Friday I think he still had the ache but we didn't discuss it much we just got on with it</u>, erm and then Saturday, was it Saturday, we were in em, yes it was 'cause it was 'Strictly Come Dancing' and, that's a Saturday, we were in Waitrose and he suddenly said that pain is getting worse ...so, by this time I thought it can't be a heart attack because they did the blood tests and everything they spent ages on him on that Tuesday, so we just sort of ignored it but he was very quiet driving back but I really didn't give it a second thought really until he got back, he said I'm going to have a bath or something and the kids were here, Jenny was, and <u>em he came down he opened this door and he looked grey...and he'd looked grey on his first day in the morning and he'd looked that colour, they get a certain colour, and he stood there and I said, well we've got to, we can't ignore this, I said it won't, it just won't go away</u> and my sisters a nurse and my brother-in-laws a doctor and they've always said to me if somebody can't get comfortable, if they are fidgeting and it just won't go away...then erm, I mean they always say don't ignore chest pain anyway but you know, that's what they've always, when it gets to that point you really have got to go and do something, so when he, he did say you know I can't lie down I can't sit up so I thought right I'm going to have to get you in so I took him in, erm, which I'm not supposed to do but I did, we just went straight in, and er, took a long time for them to realise then but, em, it was one, and then <u>I worried my god he's had</u></p>	<p>1/18 – Getting on with duties, the farm, work</p> <p>1/18 – Noticed change of colour in her partner during symptoms and was pro-active in making him get some help</p> <p>1/18 – Left chest pain to last moment then drove partner in to hospital rather than ring ambulance</p>	<p>1/18 – Complicit to ignore symptoms or not told</p> <p>1/18 – Observation rather than communication alerted her to the fact her partner unwell</p>
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12.7 Appendix G: Interview Analysis – Lived Body (Extract)

Interview 1	Interview 2	Interview 3
<p>1/12 - <u>I am flat out then until the end of term. Yeah, and it is stressful, it is stressful.</u></p> <p>1/12 – Brenda finds term time teaching very stressful – she has to speed up.</p> <p>1/16 - <u>Er...well he's had one before so, erm, I was very shocked he'd had another one, erm, I think this one was more frightening because it was the second one, erm, I think we were both very frightened.</u></p> <p>1/16 – Husband has history of heart disease but despite this found second heart attack more frightening</p> <p>1/16 – Frightened by husbands sudden illness</p> <p>1/18 - then <u>I worried my god he's had that ache since Tuesday to em, Saturday. That's frightening, that's frightening, I was frightened so frightened he was going to have another one, but I thought we'd left it so long when I came home here erm, I was scared stiff he was going to have another one...because I thought second one, gosh this is getting a little bit serious, deh!</u></p> <p>1/18 – Frightened by partners symptoms and fact they had left it so long to get help,</p> <p>1/58 - <u>I think sometimes I'm scared he's gonna lose his temper, he wouldn't do anything to me, but, I don't, I've never liked a lot of confrontation, not very good at dealing with it.</u></p> <p>1/58 – Lives with fear and uncertainty due to partner's mood. Avoids confrontation with her partner which also</p>	<p>2/8 - <u>Fine, just...stressful!</u></p> <p>2/8 – Body under pressure</p> <p>2/10 – Busy and stressful in work but putting up with it</p> <p>2/10 – Stoic and trying to stay strong in face of stressful work situation</p> <p>2/32 - <u>I have been doing aqua aerobics but I've just stopped that because they are doing stuff at the swimming pool and actually its just not as good so we have stopped that part, I go zumba, I go to zumba and I'm thinking I might join The Gym and do more</u></p> <p>2/32 – Brenda also increased her activity although not sharing anything with partner</p> <p>2/32 – Trying to focus on own body but time limits</p> <p>2/32 – Partner enjoys walking but she found it boring</p> <p>2/32 – Disconnect in approach to life-style changes between her and partner</p> <p>2/36 – Relational stress remains and revolves around her partner</p> <p>2/46 - <u>Uh...(6 secs)...okay...no that doesn't bother me, that's part of what I do, I try not to get stressed because I know that might stress him as well. But I should be doing that anyway, not getting stressed (laughs).</u></p>	<p>3/4 - <u>I had chest pain and I'd had it for quite a while erm, and then it just wouldn't go away, I can't remember when it was, so, and it stayed there, oh it was the day that Jenny got her A-level results, we'd had a very stressful time.</u></p> <p>3/4 – Had chest pain which appeared related to stress. Concerning to partner and so taken to hospital</p> <p>3/4 - Past experiences with partner made more attentive to her own symptoms of chest pain</p> <p>3/4 - <u>Jacob said oh you don't ignore chest pain so he took me in and they kept me in I think because I was diabetic and thought well there is a risk, so erm, I stayed in, I stayed overnight erm...</u></p> <p>3/4 – Diabetes made more risk heart disease</p> <p>3/8 - <u>then all my family came to see me and I got stressed...erm...and I think then the nurse said oh we think you better all go and I thought then oh my god here we go, I am going to have one now, erm, and my heart rate had gone up...</u></p> <p>3/8 – Building sense of panic fed by uncertainty.</p> <p>3/8 – Panic, body out of control fed by uncertainty</p> <p>3/10 - <u>I had the most frightening thing I've ever had and I feel bad because Jacob had it and I just said oh good that's fine but I had an angiogram and I've never been through anything so frightening (tremor in voice)...</u></p>

Interview One Summary	Interview Two Summary	Interview Three Summary
<p>Brenda feels like she is racing at present due to work pressures.</p> <p>Recounts the shock she felt when her partner was first diagnosed with heart disease. However admits to being frightened more by his second heart attack. Currently living with fear and uncertainty due to her partner's volatile mood. Tries to avoid confrontation because of this so also living with certain passivity too.</p> <p>Brenda has diabetes and struggles to keep her blood sugars under control. However she sees this as secondary to her partner's problems. Brenda does not feel that diabetes is as unpredictable as heart disease.</p> <p>Appears stoic in face of her partner's crisis, and does not talk much about how her body is coping.</p>	<p>Dismissive of body under pressure due to work commitments at the moment. Recognises that this makes her more irritable and distracted from farm.</p> <p>Trying to be pro-active around own health but this is a limited venture. There appears a disconnect between her partner's health behaviour change endeavours and her own. Lacks physical strength or commitment to be involved more on the farm. This too separates her from her partner's particular life style.</p> <p>Trying to control own stress to help her partner, almost denying her own feelings, sacrificing them to avoid conflict. Sense of powerlessness to change the treadmill she is currently on. Sense too of despair that negative living is ongoing.</p>	<p>Body breakdown. Pain, panic and fear as she is admitted with chest pain. Felt isolated and under attack whilst in hospital.</p> <p>Brenda felt out of control and powerless to do anything during her crisis, certainly traumatised by it afterwards. This led to depression and a sense of wanting to separate herself from places and faces that had caused her stress over the past year. Recognised then that it had been a build-up of stress over the year and its denial that had led to this point, particularly family relations, her own physical problems and pace of work. Suddenly able to open up to partner, release feelings and pent up emotions, in this way beginning to heal. Heal not only herself but her relationship with her partner. Looking forwards to being more physically active although remains mostly an aspiration.</p>
Main Lived Body Themes 1	Main Lived Body Themes 2	Main Lived Body Themes 3
<ol style="list-style-type: none"> 1. Living at pace and under pressure 2. Frightened by partners condition 3. Passive avoidance 4. Lives in fear of partners mood swings 5. Dismissive of own body problems 	<ol style="list-style-type: none"> 1. Body under pressure due to work 2. Irritable and distracted 3. Lack of time for own body needs 4. Bottling stress and denying feelings 5. Powerless and out of balance 	<ol style="list-style-type: none"> 1. Body breakdown and switch off 2. Pain, panic and fear as stress releases 3. Rejecting and then opening up to partner 4. Healing self by healing relationship 5. Reconciliation and rebalance
Lived body changes over 12 months		
<p>Brenda is a body under strain when I first meet her. She recognises the pressure she is under and own health issues but is dismissive of these in light of her partners own crisis. Her wish to maintain equilibrium at a time of instability leaves her feeling frightened about her partner's condition or adverse reactions to her. So she is passive and avoiding in many of her behaviours. By the second interview Brenda's sense of being under pressure has grown and she is irritable and distracted because of this. She remains unable to serve her own needs, tending to bottle up stress and using denial to try and cope with her situation. She remains fearful of her partner and his condition and powerless to resolve any issues about her current lifestyle. There is a sense of increased imbalance. By the third interview Brenda has had body breakdown. Stress symptoms have spilled out as a cardiac scare and the ensuing uncertainty that such a scare brought has left her traumatised. However from this a new more balanced self as begun to emerge, one that is more open about her feelings and wanting to talk to her partner. After her crisis Brenda appears to have entered a time of healing, not only herself but in her relationship with her husband, and these seem tightly entwined. Reconciliation and rebalance has begun.</p>		

12.8

Appendix H: Interview Analysis: Lived Space (Extract)

Summary 1	Summary 2	Summary 3
<p>Brenda spends most of her time between home and school where she is a teacher. She enjoys being able to go between the two, each seen as an antidote for the other. For Brenda the farm is a tranquil place, where she can be alone with her family, whereas in school she is constantly surrounded by others. Brenda admits that work can impinge on her home life, particularly during term time, when she has to bring marking home. Brenda recognises that her partner would like her to work less ours and be at home more. She sees the farm as home. Although she is not from a farming background or works on the farm directly she recognises the pressure such a background and responsibilities put on her partner. She thinks that her view of the farm and his are probably different because of this. Where she sees beauty and tranquillity he sees work and responsibility. She also feels that the duties on the farm trap her partner there, where she has more freedom. Brenda feels that farm pressures may be partly responsible for her partner's heart disease. She remains concerned that such a lifestyle puts him at more risk than someone who is not farming. Brenda feels that she has to escape from her husband occasionally due to his moods brought on by the stress of farming and relationship with their daughter. She is concerned that he does not get quite the same opportunities to get off the farm and leave some of his stressors behind for a couple of hours. He has admitted to her that he feels isolated and lonely on the farm which does not help him with stress. There is a sense from what Brenda says that her lived space has been influenced by her partner's condition and subsequent low mood. She seems uncomfortable about how best to help him and I get the sense that they live a lot of the time around each other, rather than</p>	<p>The pressure that Brenda feels has grown due to the opposing demands of work and home life, at a time of great change. She feels trapped by her commitments to each and in an imbalance she is unable to presently control. Looking forward to opportunities to escape both with her partner. Brenda remains a distant supervisor of her partner's health behaviour change and spectator of his stressors. Feels disconnected to the sources of his stress, namely the farm and its prevailing culture. Even feels powerless to act to help his relationship with their daughter. Brenda feels it is difficult to confront her partner about how he is feeling; she relies on observation rather than communication to try and gauge his moods. This means that her home life is becoming increasingly stressful. She feels that her work does not help this situation as it fuels some of the tension between the two of them. Lack of communication is also a catalyst to much of this. It seems that the space in which Brenda lives has become more charged by the issues she recounted in our first interview. Lack of resolution seems to have brought some of them to a head. Certainly there is a sense of her feeling trapped in both work and home presently. One gets the impression that home life involves silent tensions and strategic movement away from partner depending on how she sees his prevailing mood. Lack of support of both may be the result of this current situation.</p>	<p>Brenda's lived space on this occasion is dominated by her admission to hospital for possible heart problems. She found the whole experience frightening, the fear of death and being cut off from her family was very traumatic for her. It also made her realise what her partner had been through. Being thrown in to this experience changed her perception of his. This loss of control and powerlessness felt in hospital spilled out when she then went back to the farm. Suddenly it did not feel homely any more, it was just a place where she was treated like a slave and only enjoyed the drudgery of duty. This had an effect on her relationship with a number of her close family for a while. Managed to get away with partner and began to talk about their problems whilst away. Also admitted to him how he frightened her and that they had stopped talking. On return to farm made demands on partner to change things within the farm that had long been established norms. Re-designing thier home seems to have been undertaken to re-establish a sense of homeliness for them both. Being able to break away from tradition, what is established, crossing lines, make new rules almost. Children also left at this time and this allowed them as a couple to re-assert their relationship needs within the home. A return of the daughter to the farm has threatened this and leaves Brenda worried that it may upset their new found equilibrium again.</p>

<p>together. Brenda seems happy to organise and transport her spouse but less so sitting with him to discuss his concerns. Her acknowledgement that she works long hours is not countered by any commitment to change this and one feels Brenda is reluctant to do so because work allows her lived space away from her relational pressures on the farm. Although involved in her partner's past heart attack views herself as being on the periphery of his crisis which gives the impression of wanting to stay or feeling distanced from it.</p>		
Main Themes 1	Main Themes 2	Main Themes 3
<ol style="list-style-type: none"> 1. Loves home fears the farm 2. Separates home life from farm life from work 3. Increased tension in home since angina 4. Peripheral spectator to partner's problems 5. School is escape 	<ol style="list-style-type: none"> 1. Trapped in work and home 2. Change everywhere but feeling out of control, powerless to change 3. A stranger wishing to escape partner's problems 	<ol style="list-style-type: none"> 1. Thrown into an unknown, frightening and threatening world by illness 2. Suddenly feeling changed and home now a foreign place 3. Reconciliation and chance to rebuild home-life
Changes over 12 months		
<p>Brenda lives most of her life between the farm and the school in which she works. Both seem to be complementary to the other; work is busy and social, whereas home life is on the whole peaceful and offers some solitude. She enjoys the tranquillity the farm gives her but does not involve herself in the running of it and associated politics. Recognises that the way she sees the surrounding landscape and how her partner surveys it are fundamentally different. This is due to their differing responsibilities to the farm and her partner being 'the farmer'. Whilst Brenda feels he is trapped by the farm she can at least escape it as a teacher. She recognises that part of her partner's health problems may be related to the farm and his inability to break free from the duties that reside there.</p> <p>Living with her partner since he had heart disease means she has to negotiate their shared space carefully. This means it is often charged with tension as she tries to maintain the equilibrium. There is no doubt that her home space has been influenced detrimentally by her partner's condition and his reaction to it.</p> <p>By our second interview Brenda is expressing increased feelings of being trapped in work and at home. Change is everywhere and yet she seems powerless to change, space is the same but there is an increasing charge of anxiety that lies within both. The antidote to each other they originally gave seems to have waned, and this is due a sense of building pressure in each. A lack of resolution to some of their relational issues as meant Brenda feels more claustrophobic at home, with a possible growing sense of guilt when away from her partner at work. She seems embroiled and yet detached in her predicament.</p> <p>At our final interview Brenda has faced rift in her lived space experiences which started when she was admitted to hospital with her own cardiac scare. Her experience of the hospital was not a positive one – she is left traumatised by the sense of fear, utter powerlessness and loneliness she felt there. On discharge she somehow feels detached from the farm seeing it as just a place and not home. Over time this returns but it does so with a desire to change their living space and give it a new identity. She recognises that their children leaving home may have had something to do with her initial stressors but now this is seen positively. Having established a new more open relationship with her partner she feels their home as regained its peacefulness and tranquillity which she is benefiting from.</p>		

12.9 Appendix I: Individual Analysis – Lived Time (Extract)

Interview One Summary	Interview Two Summary	Interview Three Summary
<p>Brenda seems surprised by her past and you can almost hear her say 'how did I get here' as she recalls it to me. Hers is not a farming heritage and she underlines that it still isn't. So one is left feeling there is some disjointedness in her attunement. A difficulty accepting who she predominantly might be – farmer's wife or teacher.</p> <p>Certainly farming has not been kind to Brenda and her family, numerous family difficulties and constant worry about its profitability make theirs an unstable past. Brenda feels that her partner continues to be trapped by its history and expected cultural norms; which she is not part of. He has admitted to her in the past what an isolated and lonely existence it can be. Yet she thinks despite this he would be reluctant to sell the farm. Although they have engineered that the children will not have to rely upon it or feel the same way about having to take it over.</p> <p>Added to this Brenda currently feels powerless to know how to help her husband's current plight, the stress of the farm but with the added complication of heart disease. Understanding in a temporal sense is somewhat limited presently, through uncertainty about his future health. So too the future of the farm and inevitably her home and happiness.</p> <p>Fallenness (as in taking for granted ways of being and doing) are currently being challenged. They are just getting over her husband's second heart attack and trying to come to terms with how to deal with it and what he can do to prevent a third. So everydayness is not so automatic.</p>	<p>Brenda's present is one of increased pressure since our last meeting. Her work life-balance is further out of equilibrium and she feels more out of control of here situation. Although currently trapped by work commitments herself she hopes that this is only in the short term. Her partner would like her to give teaching up but she enjoys her work and feels it is an escape from the farm. However she recognises that for the sake of her relationship and their future prosperity she needs to limit how much she is at work.</p> <p>With regards to her partner she is more watchful of him currently, although not so worried; he has begun to make positive life changes, unlike her. She finds it difficult to know what his future plans are because these have not been communicated. However she is relieved that her powerlessness earlier in his recovery can now be replaced by supervision, although somewhat distant.</p> <p>The present is a time of change in all areas of her life, work and home. She feels there is a need to change in herself but the future remains uncertain and she seems powerless or not ready to commit to such changes yet.</p>	<p>We meet Brenda on this third occasion she is still recovering from a health scare of her own. Her recent past contains almost an epiphany that has changed her view of her situation. The shock of a possible heart attack led Brenda to spiral in to a depression where time almost stopped for her – certainly the trappings of her life did for several weeks. Following this breakdown there is a clarity about her past and understanding of her partner that she did not have before. She recognises how repeatedly stressful the last year has been for her and indeed how she denied much of what was happening around her to try and cope.</p> <p>She sees how the past was not always a threatening place for their relationship and that over time things deteriorated where it was once a better place.</p> <p>All their children have now left home and Brenda also admits that may be this had an effect upon her. However since then and now in the present her relationship with her partner is much brighter and more positive. They are communicating much more and she is pleased that she has gained some control again for the sake of their relationship rather than hers or his needs alone.</p> <p>She is now moving towards health behaviour change and not only that but her partner is supporting her to do so; in a way that she was not able to support him. She sees the present as a turning point from which they can hopefully move more positively forwards.</p>

The past seems to be a place of frustration, the present certainly one of hesitant uncertainty and finally the future is looked to with only a short lens, very much dependent upon her partners recovery.		
Main Themes 1	Main Themes 2	Main Themes 3
<ol style="list-style-type: none"> 1. Past offers only frustration in the present 2. Trapped by partners history in present 3. Future foreshortened by concern 	<ol style="list-style-type: none"> 1. Present out of control due to multiple roles 2. A time of transition, wants to change things 3. Uncertainty remains about future 	<ol style="list-style-type: none"> 1. Repatriation with her past. 2. Accepting change as part of live 3. More positive future by accepting change
Lived Time changes over 12 months		
<p>At our first meeting and on questioning about her past Brenda recounts a certain uncertainty about how she got to this current point and a lack of certainty about her attunement that is moving on from here. Her partner's health scare as blunted the future for her presently, so tied up is it with his. The present is charged with anxieties where the fallenness of everydayness seems a little strained. At our second meeting the same future uncertainties remain, with the added consideration of whether she should alter her work practices. Change is all around Brenda, her partner is making health changes, her daughter is preparing to leave home and yet she seems strangely stuck in the present, almost a timeless spectator lacking the inertia to go forwards. At our third meeting there has been a shift in Brenda's temporality. Not only as time passed but there is a perception change noted as we talk. A period of crisis due to a heart scare caused a complete breakdown in lived time. It stopped as she spiralled into an emotional breakdown. However from this a revived sense of hope, moving forwards and regard of a more positive future emerged. An increased openness between Brenda and her partner has allowed her temporal view to expand once again, seeing the past and their relationship there as positive and suddenly using this to build bridges between them. Recognising too actions in the present will have the knock on desired effect in the future for their relationship. In this way becoming more empowered again to act within a temporal sphere to create change.</p>		

12.10 Appendix J: Individual Analysis – Lived Relations (Extract)

Interview One Summary	Interview Two Summary	Interview Three Summary
<p>Brenda finds it difficult to talk to her partner about his heart disease. She finds his low mood and anger almost a barrier that she is afraid to cross. Ever since his first heart attack they have failed to tell each other how they feel. She has been dutiful in her support of him but there remains a sense of standing back, apprehensive about how to care for him.</p> <p>Brenda does not like confrontation and so lives with heightened anxiety about her partner's wellbeing. Brenda is unsure how partner's condition affects other members of family; certainly she sees that her daughter and he have a stressful relationship too. Brenda turns to her younger sister for support. Brenda recognises that partner's profession does not help his state of mind – he is isolated and alone most of the day, or certainly was in the past before they built houses on the farm. She is happy for him to seek support from others but seems powerless to give it herself; even though her mood, her happiness is allied to his. Brenda feels their future prosperity has been put in jeopardy by this last attack, and so there is a lack of equilibrium at present. She remains fearful of the future.</p>	<p>Work pressure is affecting Brenda's relationship with her partner presently. Fortunately he has made good progress and has modified his lifestyle to try and prevent any further cardiac issues. This is contrast to her however and Brenda does not share her partner's activities.</p> <p>Relational stress still exists at the farm, through lack of communication and issues with daughter. Brenda remains somewhat a spectator powerless to affect these stressors and yet affected by them. Tries to remain the dutiful wife and does care for her partner despite struggling to understand him. Her daughters apparent inconsideration causes Brenda stress to. Future plans remain uncertain; Brenda has not discussed this with partner although she thinks he would like her to give up teaching. She would also like to reduce hours and thinks that would help their relationship, although remains committed to teaching. However remains very much on eggshells about her relationship with partner, relies on observation rather than discussion to gauge his mood. Recognises changes need to be made to improve their relationship, most probably linked to how many hours she works.</p>	<p>Brenda had her own cardiac scare and felt very isolated by an admission to hospital. Recognised how close and important her family were to her. However after her discharge she found it difficult to cope and a series of fall outs with family members led her to try and isolate herself, using only her sister to confide in initially. Turning away from all those who had given her stress over the past year, mainly her partner, daughter and mother. Recognised that a build-up stressors linked her relationships at home, work pressures and own physical problems led to breakdown. Felt undervalued and out of control. During this crisis though partner did step up to support her; being able to empathise through his own experiences. This acted as a catalyst to more open discussion between them. Brenda was able to tell him how she felt and how his behaviour had affected her, but was now able to sympathise with him also. Recognises too that she lacked any real understanding of what her partner went through and regrets this. However since her scare they have been able to communicate more openly and are trying to improve their relationship. Daughter still poses threat to their relationship because of the effect she has on her father but the two of them are working together now to deal with this.</p>
Main Themes 1	Main Themes 2	Main Themes 3
<ol style="list-style-type: none"> 1. Frightened to talk 2. Feelings hidden 3. Uncertainty within family 4. Sister supports 5. Powerless in support to partner 	<ol style="list-style-type: none"> 1. Lack of sharing of experiences 2. Dutiful but struggles to understand partner 3. Relies on observation rather than discussion 4. Future prosperity uncertain 	<ol style="list-style-type: none"> 1. Cutting off relationships during own crisis 2. Confiding only in sister 3. Partner stepping up to support 4. Opening up feelings increasing talk 5. Family stressors remain but working together to resolve

Lived Relation changes over 12 months

When I first meet Brenda she is at a loss to know how to improve her relationship with her partner which had suffered due to his condition, response to it and their inability to discuss this together. She feels a duty to support him but certain inability to care. Her vocation is her focus. She finds her relationship with her daughter stressful but that of her sister supportive. Brenda thinks that her partners farming role does not help his circumstance but she also feels unable to help here too. Yet her happiness and future prosperity are tied up in this relationship and there is a sense of panic almost that she feels powerless to affect things positively. Six months later and relations are no better, with increased pressure from her work not helping their situation. Here partner has made his own lifestyle changes to combat heart disease but Brenda does not feel a part of these. Brenda appears increasingly a spectator in her own family, powerless to change the course she on and yet wants to do so. Communication remains stilted and many uncertainties about their future remain. We finally meet with Brenda again after she has suffered a health scare which challenges her relationship with all her close family other than her sister, in whom she continues to confide. She admits to feeling undervalued and overlooked by her partner and children, a slave in her own home. This is magnified by her own inability to act in some ways, doing so only after crisis. Through her own crisis there is a reconciliation of sorts between her and her partner, Brenda finding herself suddenly able to be open and truthful with him. She also recognises too that she lacked any understanding of her partners own crisis and this highlights too that she was possibly too self-serving in the past, whereas as now she acts to help their relationship. Some other family relational issues challenge their new sense of equilibrium but Brenda is working with her partner to hopefully minimise this likelihood.

12.11 Appendix K: NVivo8 Screenshots of Data Manipulation

Diagram I: NVivo8 screen page highlighting (i) grouping of farmers and partners in to two 'internal' folder; (ii) List of Angina Sufferer interview folders and (iii) interview transcription of Colin's first interview.

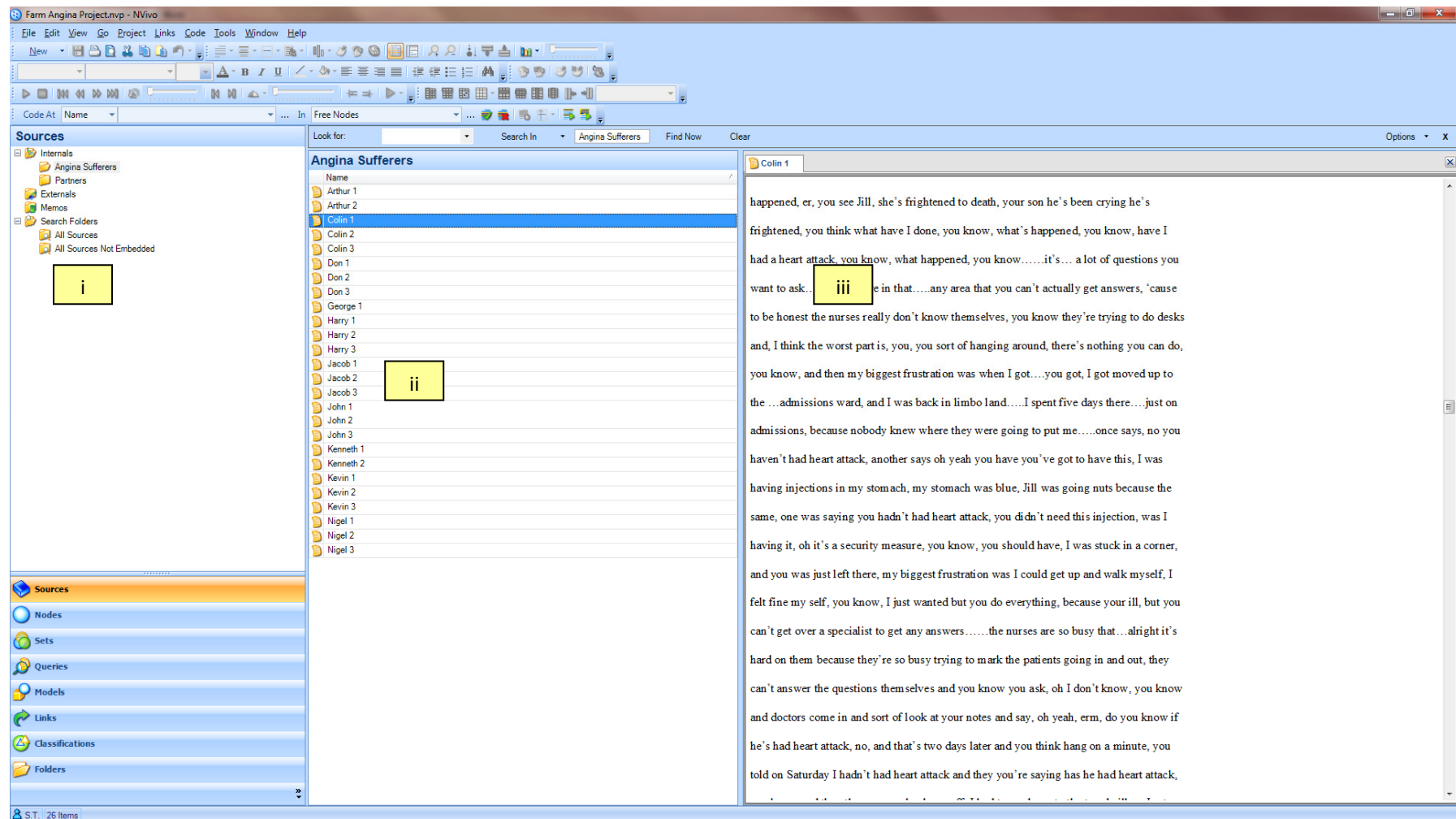


Diagram II: NVivo8 screen page highlighting (i) tree node categories divided into four lifeworld existentials (spatiality, corporeality, temporality and relationality) over three participant interviews (S = sufferer; P = partner; 1-3 = interview) subcategories of 'Lived Time' at angina sufferer second interviews (ii) (S2) and (iii) angina sufferers 'living day to day' theme revealed during second interviews.

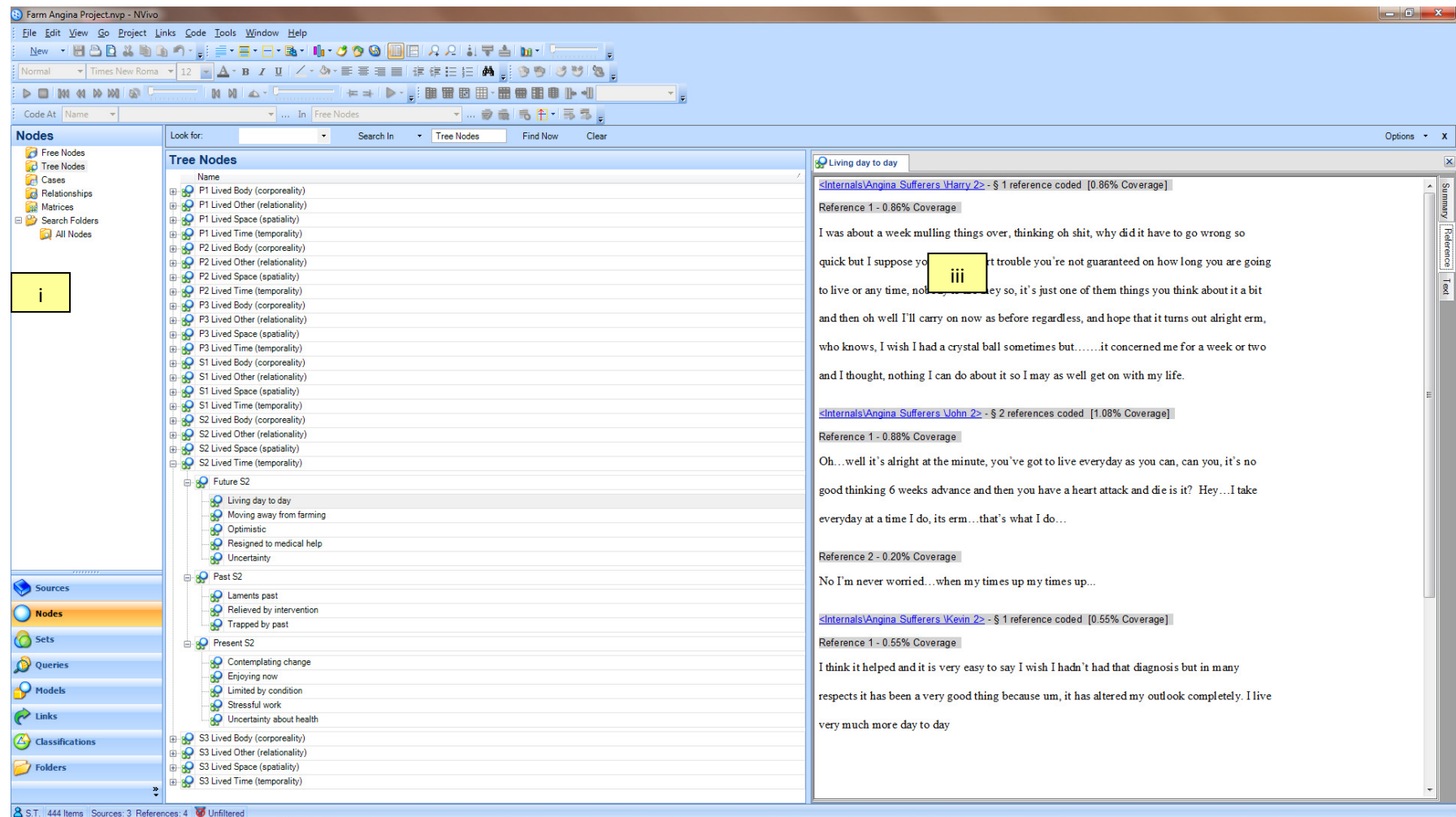
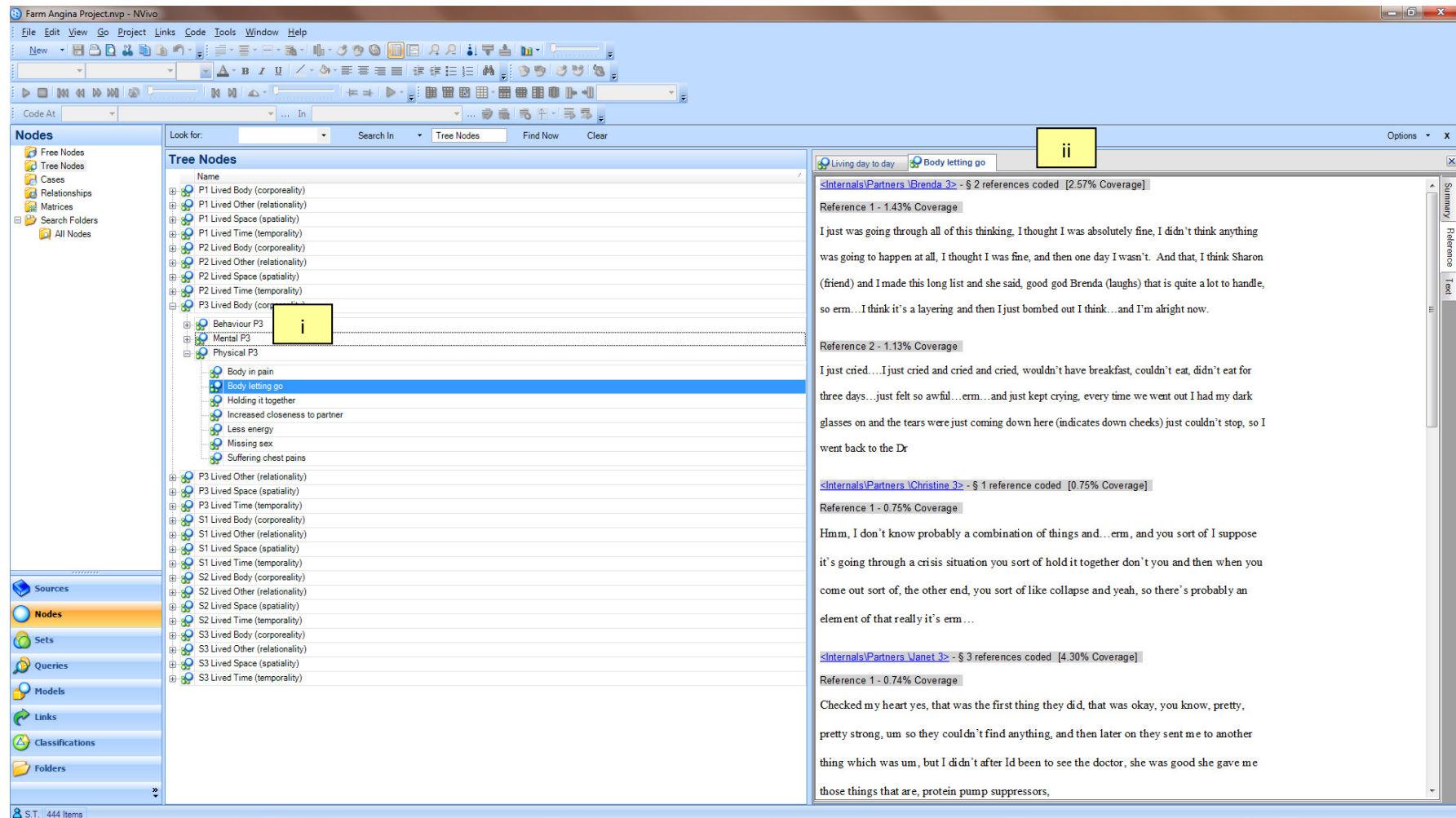


Diagram III: NVivo8 screen page highlighting partner comments under (i) 'Lived Body' (corporeality) existential regarding (ii) having a physical sense of their '*bodies letting go*' during third interviews.



12.12 **Appendix L: The Wellbeing Lattice & Suffering Lattice, taken from Galvin and Todres (2013)**

Wellbeing Lattice:

	Mobility	Dwelling	Dwelling-Mobility
Spatiality	Adventurous horizons	At-homeness	Abiding Expanse
Temporality	Future Orientation	Present centredness	Renewal
Inter-subjectivity	Mysterious interpersonal attraction	Kinship and belonging	Mutual complementarity
Mood	Excitement and desire	Peacefulness	Mirror-like multidimensional fullness
Identity	I can	I am	Layered Continuity
Embodiment	Vitality	Comfort	Grounded vibrancy

Suffering Lattice:

	Mobility	Dwelling	Dwelling-Mobility
Spatiality	Imprisoned	Exiled	Roomless
Temporality	Blocked future	Elusive present	No respite
Inter-subjectivity	Aversion	Alienated isolation	Persecution
Mood	Depression	Agitation	Restless gloom
Identity	I am unable	I am an object or thing	I am fragmented
Embodiment	Stasis and exhaustion	Bodily discomfort and pain	Painful closing down